

**FURTHER ANALYSIS AND  
EVALUATION  
OF THE  
ADMINISTRATION ON AGING  
ALZHEIMER'S DEMONSTRATION  
GRANT TO STATES**

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## EXECUTIVE SUMMARY

### AOA FURTHER ANALYSIS AND EVALUATION OF THE ADDGS PROJECT

#### PROJECT GOAL

This report summarizes findings from three related studies that extended the initial evaluation of the Alzheimer's Demonstration Grant to States program (ADDGS) to obtain additional information about the patterns of use and delivery of respite services. The goal of the project was to capitalize on the unique longitudinal qualities of the data from the ADDGS to provide a more detailed analysis of how: (1) families use respite services; (2) families evaluate respite services in light of their beliefs, culture, and need; and (3) providers can develop appropriate and successful respite services in their own communities.

#### ALZHEIMER'S DEMONSTRATION PROGRAM

The Alzheimer's Demonstration Grants to States (ADDGS) program was authorized through section 398 of the Public Health Service (PHS) Act (P.L. 78-410) as amended by Public Law 101-157, Home Health Care and Alzheimer's Disease Amendments of 1990, and by Public Law 105-379, the Health Professions Education Partnerships Act of 1998. *The goal of this legislation was to expand support services for persons with Alzheimer's Disease and their caregivers.* Special attention has been given to reaching hard-to-serve and underserved populations. The demonstration program was intended to assist grantees in planning, establishing, and operating demonstration programs in the following areas: (1) program development; (2) services delivery; and (3) information dissemination.

Fifteen grantees were selected through two rounds of competitive requests for proposals. In September of 1992, eleven states (*California, District of Columbia, Florida, Maine, Maryland, Michigan, Montana, Ohio, Oregon, Puerto Rico, South Carolina*) received a three-year Alzheimer's Demonstration Project grant award. In July of 1993, four additional states received a demonstration grant (*Georgia, Hawaii, North Carolina, Washington*). The individual grants were then extended to each site through FY 2000.

Unlike many federal programs, the Alzheimer's Demonstration has been characterized by great local diversity in design and implementation. Although every grantee has been responsible for the creation of respite services and outreach to hard-to-reach populations, each state (or territory) has developed and executed a program of outreach and support services that was specific to the unique needs and resources of their citizens. A second hallmark of the project has been the development of cooperative partnerships among public and private organizations to integrate the new programs and services effectively into existing service environments.

In January of 1997, the Final Report for the ADDGS project documented the accomplishments of the program (Montgomery et al., 1997). At that time, nearly seven thousand families (6,983) had been served and well over one million units of respite and support services (1,039,506) were delivered through the demonstration. Of particular interest was the success of the ADDGS project in reaching under-served and under represented populations (see also Montgomery et al. 1997). African Americans/Blacks, Hispanic/Latinos, Asian/Pacific Islanders, and Native Americans/Eskimos were served through the ADDGS in numbers that exceeded their proportion of the general United States' population.

## **BACKGROUND AND RATIONALE FOR PROJECT**

### **What is Respite?**

Respite is a term used to refer to a wide range of services intended to give temporary relief to families caring for disabled members. This concept of care developed in the United States as a corollary of the early 1970s deinstitutionalization movement for developmentally disabled children and adults (Cohen, 1982). As families assumed the primary responsibility for the developmentally disabled, the need for temporary relief from their caregiving responsibilities created a demand for respite services. Recognition, in the United States, of the parallel need for relief of family members caring for frail and disabled elderly did not emerge until the mid 1980s when formal respite services were initially developed as demonstration projects.

While there is general consensus that respite means "an interval of temporary relief," there is almost no agreement as to the composition of the services that are to provide relief. Respite programs have ranged from volunteers providing short periods of companionship to short stays in institutions. Services can be provided in a client's home (in-home services), in a group or institutional setting (out-of-home service), or in multiple settings (combination programs). Out-of-home services include foster homes, adult day care centers, respite facilities, nursing homes, and hospitals. The only element common to these services is the intent to provide a period of relief for caregivers.

Within the three general types of respite settings, there are a number of possible variations depending upon the level of care, the types of activities available to participants, and the duration and frequency of respite episodes. Programs may vary along a continuum from low to high levels of care, and respite episodes may range from short periods of a few hours to long stays of up to six weeks. Clients may be able to use services as frequently as once or twice a week or as infrequently as once or twice a year.

### **Contributions of this Project**

Currently there is overwhelming consensus among families and service providers that respite services are the most desired and needed support for families caring for persons with Alzheimer's disease or other dementias. There is also a pervasive belief that respite care can relieve the burden of the caregiving situation and, perhaps, even allow families to continue to care for relatives who otherwise might have been institutionalized. This perspective tends to be accompanied by the belief that respite programs will reduce the costs of long term care by reducing or delaying the need for more costly forms of care.

To a large extent, any empirical evidence to demonstrate the psychological and monetary benefits of respite remains sparse and uneven because respite remains an amorphous notion that has not been systematically studied. Unlike pharmaceutical studies, which use rigid protocols to control the content and quantity of a treatment, respite as a treatment has varied widely in composition and quantity both among studies and within single studies. Insufficient attention has been given to describing service interventions or patterns of service use over time (Lawton, Brody and Saperstein, 1989; Montgomery and Borgatta, 1989).

The question as to whether respite services ultimately reduce the cost of long term care remains an important policy issue. Yet the question remains largely unanswered because little is truly known about how caregivers opt to use respite services when they are available. Despite growing evidence that respite services, indeed, do help families continue in their caregiving role for a longer period of time (see Montgomery and Kosloski, 1995), there is little systematic knowledge about long-term patterns of respite service use *in situ*.

Basic information about patterns of respite use is necessary for practitioners to plan and implement respite programs. For example, in a real life setting, how much respite will a family use? Over what period of time do families use respite and at what level of intensity? How do these patterns differ for different types of respite programs (i.e., in-home or ADC)? How do constraints in respite availability alter patterns of use? Are there differences in use patterns associated with type of caregiver (spouse/adult child) or with disability level of the elder or with geographic regions or by differing cultural backgrounds? Answers to these questions are extremely important for the development of effective and efficient support programs and long term care policies. This project entailed three related studies that were undertaken to address these critical questions about the use of respite services.

## STUDY ONE: ASSESSING CULTURAL AND STRUCTURAL BARRIERS TO SERVICE USE

### Purpose of Study One

The central purpose of study one was to identify differences among cultural groups in their beliefs about family caregiving and their views of respite services offered through the ADDGS program. The links between culture and belief systems, perceptions of service accessibility, and client satisfaction were explored in detail. For this study, culture was defined in terms of three variables: ethnicity, family relationship, and geographic location. Each of these dimensions of diversity was examined as a factor potentially affecting clients' beliefs about caregiving and views of program services.

### Methods

**Sample.** Telephone interviews, using a computer assisted telephone interview (CATI) system, were conducted with a culturally diverse sample of 377 client caregivers from the ADDGS project. The sample included 45% White, 31% Black/African-American, and 25% Hispanic/Latino caregivers.

**Measures.** Eleven composite variables were constructed to measure aspects of caregivers' beliefs about aging and responsibilities for care. These measures included *affection for elder, obligation to care, family values, respect for elders, desired frequency of social contact, guilt at respite use, attitudes toward government assistance, satisfaction with help with caregiving, religiosity, strength of beliefs, and support provided by religious congregation*

Nine composite variables were constructed to measure caregivers' perceptions of access and/or barriers to service use. These included *client satisfaction, communication difficulties, clear expectations, access to services, friendliness of staff, shared values with staff, institutional barriers, trust in staff, and appropriateness of activities.*

**Analyses.** Analysis of variance was used to examine differences between cultural groups in beliefs systems. Multiple regression procedures were used to identify predictors of client satisfaction.

### Findings

#### ***Attitudes and Beliefs***

As anticipated, members of different ethnic, geographic, and relationship groups held markedly different beliefs about various aspects of family relationships, responsibilities for care, and the conditions for appropriate use of outside services. Differences were observed between ethnic groups on 9 of the 11 measures of caregiver beliefs and attitudes about filial care and responsibility. In contrast only one difference in beliefs was associated with geography and two differences were associated with the family relationship of the caregiver to the elder.

- Whites reported lower levels of affection for the care recipients and less adherence to family values. Whites also expressed the highest level of guilt for using support services and were least likely to endorse the responsibility of government to provide support services.
- Hispanic/Latinos reported the highest level of adherence to family values and the greatest respect for elders. As a group, Hispanics/Latinos were also most satisfied with the levels of social contact they currently experienced and the level of help they received.

- Black/African-Americans reported the highest levels of religiosity, the greatest strength of belief in God, and the highest levels of support from religious communities.
- Spouses expressed greater affection for the care recipients and greater obligation to provide care than did children or other groups of caregivers. Spouses also reported significantly less family conflict.
- Caregivers in urban areas reported greater respect for the elder than those residing in rural areas.

Cultural differences in views of services were identified for only two aspects of service programs. Hispanic/Latino caregivers reported greater difficulty with communication relative to other groups. Notably, Whites reported the lowest levels for accessibility of services.

### ***Satisfaction***

Perhaps the most important finding was that there were no differences in client satisfaction with the demonstration services associated with ethnicity, relationship to the elder, geographic location or type of respite. Moreover, all levels of satisfaction were uniformly high, averaging nearly 14 on a scale ranging from 3 (low) to 15 (high).

The most satisfied day care clients were those who: (1) received high levels of support and comfort from their religious congregation (2) had clear expectations regarding the program services; (3) judged the respite services to be appropriate for the client; and (4) perceived the "red tape" to be minimal.

Clients of in-home services were most satisfied when they: (1) had clear expectations regarding the program services; (2) perceived the respite services to be accessible at the times they need it; and (3) judged the program staff to be friendly.

### ***Practice Implications***

Four factors that are under the control of practitioners were found to be related to client satisfaction. These findings suggest that clients will be most satisfied when service providers:

- convey a clear understanding to caregivers as to what a respite program will and will not do in providing care for the individual with AD;
- reduce the amount of red tape associated with the program;
- provide activities that caregivers believe to be appropriate for their family members; and
- are flexible with the amount of service that is made available and the times at which it can be used.

## STUDY TWO: IDENTIFICATION OF PROFILES OF RESPITE SERVICE USE

### Purpose of Study Two

The primary purpose of study two was to identify and document long term profiles of respite use among a diverse sample of families caring for elders with dementia. These profiles are potentially useful planning tools for policy makers and service providers responsible for implementing effective and efficient respite programs. This study capitalized on the unique qualities of the data from the Alzheimer's Demonstration Grant to States (ADDGS) that have been gathered over the past seven years.

The diversity of caregivers and their caregiving contexts is now well established by a large body of research conducted over the past two decades. This study was undertaken with the expectation that diversity among caregivers and their contexts would likely be reflected in their patterns of respite use. Specifically, three sets of variables were investigated as plausible factors affecting patterns of service use: cultural differences; differing caregiving careers; and service availability.

### Study Questions

Four basic questions concerning patterns of respite use among a diverse sample of families caring for an elder with dementia were addressed:

1. What is the duration of respite use?
2. How much respite is used?
3. How consistently or continuously do families use respite?
4. Do patterns of service use change over time?

Additionally, the analysis also focused on three related questions pertaining to differences in patterns of respite use that are likely to be associated with characteristics of families and/or providers:

5. Do patterns of respite use differ by type of respite service (e.g. in-home or day care)?
6. To what extent are patterns of respite use associated with characteristics of the caregiver or elder?
7. To what extent are patterns of respite use associated with characteristics of service providers?

### Methods

**Sample.** Data were gathered from 4,369 client families and 122 service providers who participated in the ADDGS demonstration in the District of Columbia, Florida, Maine, Michigan, North Carolina, South Carolina, and Washington. Of the 2193 clients using day care services, 640 were brief users and 1553 were extended users. Of the 2690 clients using in-home services, 831 were brief users and 1859 were extended users.

**Data Collection.** Information about demographic and functional status of elders and caregivers was gathered as part of the client intake process. Data pertaining to clients' use of services were taken from providers' records. Telephone interviews were conducted with key staff members to obtain programmatic information from the 122 agencies providing respite services in day care and in-home settings.

**Measures of Service Use.** Although most previous studies have quantified the amount of service use in terms of total hours of respite used, this summary value does not capture the many ways that families may differ in their use of services. Families may vary in (1) the number

of hours that is used on each occasion, (2) the duration of time (e.g. number of months) over which a family actually uses services, (3) the continuity of use within that duration period, and (4) the total number of hours of respite that is used. It is not only plausible that families will vary in their patterns of use as conceptualized and measured in these different ways, but it is also likely that a different set of factors may account for the variation in the different measures of use. Therefore, to fully describe patterns of respite use and capture differences among families in their patterns of use, it is important to conceptualize and measure use in several different ways. The **intensity** of respite was defined as the number of hours used in each month. The **duration** of respite use was defined as the number of months between the client's first occasion of use and the last occasion of use. The **continuity** of respite use was measured as the ratio of number of months in which a family actually used the respite services relative to the number of months for which the family was eligible to use services. The **total hours** of respite used by a client is equal to the sum of all hours used over the eligibility period. (The **eligibility period** was defined as the period between enrollment in the demonstration project and departure from the project for any reason.)

**Strategy for Data Analysis.** Two sets of analyses were conducted to fully describe the patterns of respite use by clients. The first set of analyses focused on clients who used services for only a brief period. These analyses included all clients who limited their use of respite services to one or two months. Both descriptive statistics and logistic regression techniques were used to identify key characteristics of these brief users.

The second set of analyses focused on clients who used services for three or more months. Regression techniques and hierarchical linear modeling procedures were used to identify and describe their patterns of respite use.

## **Findings**

### ***Brief Users***

Almost one third of the demonstration clients used respite services for only one or two months and the mean length of use was ten months. White clients were most likely to be brief users. Black/African-Americans were least likely to be brief term users of day care and Hispanic/Latino clients are least likely to be brief users of in-home. This pattern may reflect the success of the ADDGS demonstration with promoting programs that effectively serve traditionally under-served populations.

The decision by clients to continue or discontinue use of services is related to characteristics of the service providers. The positive relationship observed between brief user status and problem behaviors likely reflects the limited capacity of day care providers to care for persons with problem behaviors. As long as elders are able to function in a day care setting, they continue to use that service. When elder impairment becomes too high, families are likely to seek in-home services. Day care is most often used as a support system when caregivers must be away from home or when caregivers have other obligations that require their attention. When the impairment level of the elder increases to higher levels, adult children who cannot leave a parent home along are more likely to cease caregiving.

Brief users of in-home respite appear to constitute a sub-population of caregivers with unmet needs who have a greater need for professional health and household assistance. Consequently they tend to discontinue use of programs that are staffed by volunteers that do not provide health related services and that often do not have set fee structures

### ***Extended Users***

For extended users of respite, mean duration of service use is 16.2 months for day care clients and 14.9 months for in-home use. Day care clients use twice as many hours of service each month (50.3 versus 24.6) and almost three times (817 versus 283) as many hours of care over their full duration of service use.

**Client characteristics are the primary predictors of the duration, continuity and intensity of service used.** Persons with high levels of IADL impairment used day care services a shorter duration, but with greater intensity. Among users of in-home respite, higher levels of ADL impairment and problem behaviors were associated with more intense use of services. For users of both types of services, the number of hours of service used each month increased with duration.

Clients assisted by a spouse were more frequent users of in-home respite programs, but they used significantly fewer hours of respite each month than did their peers who were cared for by an adult child or other more distant relative. Elders with male caregivers used more respite services.

Different ethnic groups had distinct trajectories of day care use over time. Compared to Whites, Blacks/African-Americans used smaller quantities of service over a more extended period of time. Hispanic/Latino elders used high quantities of service for short periods. Notably, the two groups of minorities did not differ in the average total number of hours of day care used.

Middle-income elders were the highest users of in-home services. For this client group, in-home respite is probably the most economical solution for long term care because of limited discretionary money and ineligibility for Medicaid as a source of payment for nursing home care.

### **Two provider characteristics influence the intensity respite service use over time.**

Families who sought respite from programs that offer health care services used services more intensely. This trend likely reflects higher levels of elder need. In general, clients used services more intensely when the maximum limit for services was higher, although they did not necessarily use more services over the duration of their use. This pattern suggests that arbitrary caps on services may impede effective distribution of resources among clients with different levels of need.

### **PRACTICE IMPLICATIONS**

Accurate cost estimates for respite services cannot be made without clear knowledge of client variations in the duration, continuity, and intensity of respite use. When providers plan and budget for respite services, it is useful for them to consider the characteristics of their client population, which are directly linked to variations in patterns of use.

- It is important to offer multiple forms of respite to meet the needs of different segments of the client population and to provide ongoing support for families, as needs change over time.
- When designing respite services, attention should be given to both the level of care provided and the type of respite services offered.
- Limitations placed by providers on the number of hours of service available to clients are likely to create significant barriers to service use if they are not appropriately tailored to match client characteristics.

### **STUDY THREE: STAFF VIEWS ABOUT SUCCESSFUL STRATEGIES FOR ADDRESSING CULTURAL BARRIERS TO SERVICE**

#### **Purpose of Study Three**

The purpose of study three was to provide a more detailed understanding of the issues confronting providers as they attempted to successfully develop and implement culturally appropriate support services for diverse populations. Qualitative methods were used to explore more fully the ethnic, geographic and familial contexts of service delivery from the perspective of service providers. Data were gathered through interviews with key service delivery staff who discussed successful strategies for addressing cultural and/or structural barriers to service use.

#### **Methods**

**Sample.** Fifty qualitative interviews were completed. Forty-two interviewees were frontline staff members and eight were administrators. Programs that targeted urban dwelling Hispanic/Latino families employed fifteen of the staff members and ten worked for programs that served urban Black/African-Americans. Of the twenty-five staff members employed by programs that served rural populations, eight provided respite to Black/African-American families while four served rural Hispanic/Latinos. The remaining thirteen staff members were employed in programs that served rural families of all ethnic groups.

**Data Collection.** Interviews were conducted by telephone and then tape recorded for later transcription. Questions followed an interview guide and proceeded in an open ended, in-depth format in accordance with standard qualitative methodology.

#### **Findings**

Staff members offered general and specific information about the qualities of the communities they served. The interviews revealed both unique beliefs and needs of the three target populations (rural, Black/African-Americans, Hispanic/Latinos) as well as needs that were shared by all three of the client groups. Staff members also described a range of strategies for successfully serving these client groups

#### ***Serving Rural Communities***

**Important Client Characteristics.** Providers in rural communities stressed the importance of recognizing the unique culture of these areas. In general, rural individuals were relatively isolated and had fewer opportunities for education, medical care, and other services. There was a tendency to rely on oneself, one's family, and one's church, and a strong ideology of independence. The relationships to family and church were very strong and central within rural communities. Because of the small size of the communities, there was also an enhanced level of familiarity among residents. There was also a general distrust of outsiders, including service staff, service agencies, researchers, and government institutions.

A lack of general knowledge and understanding of Alzheimer's disease was pervasive. Most families were dependent upon their family doctors for dementia specifics. Unfortunately, rural physicians, especially those who have been practicing for a number of years, often had little training about Alzheimer's disease nor awareness of the possible treatments.

**Barriers to Service Delivery.** Providers reported that in the rural areas there was often a stigma attached to the use of support services because they were often viewed as welfare a public handout. This stigma created a serious barrier to service delivery, especially for less educated families. Additionally, rural clients preferred staff members of similar ethnicity, religion and gender to the elder. Providers also identified isolation of rural locations, shortage of trained

staff, limited resources, and transportation as barriers to delivering quality services in rural areas.

### ***Serving Black/African-American Communities***

**Important Client Characteristics.** Black/African-American communities were recognized for their strong sense of extended family and community ties. This client community had a greater prevalence of working caregivers, primary caregivers who were more distant relatives, and wider family involvement in caregiving. Providers observed that Black/African-Americans valued their ability to remain self-sufficient and “take care of their own”. They also shared a pervasive mistrust of government assistance as well as the medical system. Spirituality and organized religion had an important role, both to the Black/African-American community in general, and as a support structure for individual caregivers. The expression of respect among community members was also very important.

**Barriers to Service Delivery.** Two issues were identified by providers as particularly unique challenges for serving Black/African American communities. First, providers noted that families seemed to take the challenge of Alzheimer’s disease in stride and were realistic in dealing with the related care tasks. Consequently, they often did not seek or readily accept help. Younger caregivers, however, were more receptive to service use than older caregivers. Second, members of the Black/African-American community expressed feelings of initial reluctance to accept a White care provider. This reluctance appeared to be related to historical issues of mistrust and social mores between the groups. In addition to these unique challenges, staff members identified several structural barriers to providing services: scarce funding, distrust of government services, and suspicion of the medical research community.

### ***Serving Hispanic/Latino Communities***

**Important Client Characteristics.** Providers within the Hispanic/Latino communities stressed the wide diversity within this population which includes persons of many nationalities who vary greatly in culture, dialects, and etiquette. Many clients were monolingual Spanish-speakers with relatively low levels of literacy that resulted in isolation from mainstream services. These clients particularly valued one-on-one relationships with service providers. When using services, Hispanic/Latino families were most comfortable with bicultural staff members that were familiar with their community, their nationality, and spoke Spanish. Providers also reported that younger caregivers were more receptive to service use than older caregivers. Despite the diversity in cultural norms within the Hispanic/Latino community, providers noted a common expectation that the family unit should solve family problems and provide needed care. Additionally, gestures of respect were considered important, and differed by nationality.

Families in this community sometimes feared that Alzheimer’s disease was a form of insanity. Additionally, they believed that dementia symptoms were a “curse” or a punishment for previous “bad” behavior. Other common responses included religious explanation such as the caregivers’ cross to bear or the elder’s possession by evil spirits. These beliefs led families to seek non-medical cures. Many Hispanic/Latino families did not value Western medical treatments and if they did seek care from a physician, they were often not diagnosed appropriately.

**Barriers to Service Delivery.** The unique qualities of the Hispanic/Latino clients created several barriers to effective service provision. In every setting, language represented a significant barrier to service use for this group. Providers within the Hispanic/Latino populations also identified the strong cultural value of family caregiving, a pervasive mistrust of the government, a preference for folk or home remedies, and difficulties maneuvering through complex bureaucracies as barriers faced by these communities.

### ***Common Barriers***

Three themes were common among providers serving all three communities. Each group was described as having an ideology of self-sufficiency that emphasized reliance on family. Providers also perceived these client groups to have a general distrust of the government and of any services affiliated with it. Additionally each group was described as having a lack of knowledge about Alzheimer's disease.

### **Strategies for Overcoming Barriers.**

Providers identified four general strategies that they used to address the barriers to service delivery in these communities. These strategies recognized the cultural beliefs of these underserved communities and can be characterized as both innovative and responsive to client needs.

***First, when approaching clients in these underserved communities, providers described and emphasized their services, as programs that would complement and supplement, not replace family care.*** For example, within the Hispanic/Latino communities, providers were more successful in their outreach strategies when caregivers were assured that they were not alone in dealing with dementia, and that seeking assistance is not neglectful of familial duties. In rural areas, providers also attended to the concern of respite as a handout by charging a nominal fee for the services.

***Second, to overcome resistance to formal support services, social aspects of care were emphasized and programs were designed to include activities that were familiar to the clients.*** For example, within the Hispanic/Latino communities, providers found it helpful to offer traditional food, and to celebrate national holidays of their clients' home countries. In general, successful programs strived to provide services in a friendly, home-like manner relying on familiar activities, often based in music or religion. Similarly, providers developed service activities around social themes in non-institutional settings, such as referring to support groups as "clubs" or "tea-time," which were more likely to be accepted by both Black/African-Americans and Hispanic/Latino clients. Support groups were also better attended when they were combined with a potluck dinner or luncheon.

***Third, providers developed strategies to help families obtain better information about Alzheimer's disease and health care.*** Within the Hispanic/Latino communities, providers acknowledged folk beliefs as a place to begin in educating about dementia. Assistance with filling out forms and applications was also provided to help families negotiate health care systems and obtain benefits for which they were eligible. In rural communities, providers focused on empowering families in talking with their physicians to obtain a diagnosis or more medical information.

Finally, providers tailored and individualized services to better meet the unique needs and concerns of their client populations. For example, the prevalence of working caregivers in the Black/African-American community led some providers to conduct seminars within large workplaces, and to extend day care hours. Providers also noted the importance of instructing workers to address Black/African clients respectfully as Mister or Misses. To serve Hispanic/Latino clients, providers developed bilingual services and were successful at cultivating bicultural staff members. The small size of most rural agencies allowed providers to individualize care plans to match clients with familiar aides. Rural providers were also creative in devising solutions to the barriers bred by isolation. Examples included long-distance support groups and information newsletters, as well as more extensive transportation networks.

## CONCLUSION

### Major Themes

This set of related studies was undertaken with the knowledge that most service providers believe respite programs are both desired by, and useful for, families caring for persons afflicted with Alzheimer's disease. The focus of the research has been on the manner in which a diverse population of caregiving families used respite service, the beliefs of these families about caregiving and their preferences for services. The report includes a large number of findings regarding behaviors and preferences of family members who provide care for their relatives. These findings are summarized under four major themes.

1. There is great diversity among caregivers in the contexts within which they provide care and their beliefs about family and government obligations. These differences are primarily associated with ethnicity and the relationship of the caregiver to the care recipient.
2. Diversity among caregivers created a corresponding diversity in the types of services that caregivers seek and the manner in which they use respite services. Clear patterns were observed that indicate that caregivers seek and continue to use services that they perceive as useful to their caregiving context. Similarly, caregivers ceased using services that they perceived to be inappropriate or difficult to use. Indeed, almost one third of the clients included in this study were brief users who used services for less than two months.
3. Different types of respite services meet the needs of different service populations. The distinct differences in patterns of service use that were observed for different segments of the caregiving population underscore the importance for communities to offer a respite services in different formats. Optimally, a community would offer a continuum of services. Caregivers are active agents in choosing support services. The patterns of respite use observed in the longitudinal data suggest that the choices that caregivers make are influenced by both structural factors and by caregivers' perceptions of their own needs.
4. Provider characteristics influence the patterns of use or non-use of services as well as client satisfaction with services. When making decisions about service use, families judge the appropriateness of a service for their family context and the accessibility of the service. Three sets of provider characteristics were seen to influence clients' service use: *the amount and level of service, quality of staff, and effective communication with family members.*

### Practice and Policy Implications

When the broad array of findings is considered together several general implications for program design and service delivery can be delineated.

1. The efficient and effective use of program resources dictates careful consideration of patterns of service use for different segments of the target population. These studies identified a range of different long term patterns of service use that are associated with the relationship of the caregiver to the elder and with ethnicity. To plan for future service needs, it is important to consider these trajectories in conjunction with the prevalence of the different segments of the population in the programs' catchment area.
2. When developing a new respite program, it is important to create a service that complements other services available in the community in an effort to make a full continuum available. Not all programs are appropriate for all caregivers. If a community can offer only one form of respite, it is important to learn as much as possible about the prevalence of

different types of caregiving contexts in the community in order to best meet the community's needs.

3. Existing programs may want to carefully consider the characteristics of the clients they are currently serving and note the characteristics of those who are going unserved. All policy decisions regarding availability of services reflect values about who should be served and at what cost. It is not always possible for programs to serve all segments of the caregiving population. However, it is important for policy makers to consciously consider which groups of persons they choose to serve. For example, day care programs that are not offered daily or throughout the normal workday clearly will not serve the majority of employed caregivers. A well-planned program will consider such issues carefully.
4. Once a respite program has been developed, it is important to target the services to the appropriate segments of the caregiving population. Programs that carefully target services and/or alter eligibility rules or the number of hours of service available will be able to reduce the number of families that enroll in services for only brief periods. These families can be costly to programs due to the high costs associated with the initial enrollment of clients.
5. The hiring and training of competent, caring workers is a key element in creating a successful respite program. All staff members should be trained to be sensitive to the diversity of caregiving situations and to communicate with families in an open, effective, and clear manner. Existing programs might want to assess the communication skills of their staff members and/or modify the ways in which they communicate information about the services to families. Attention needs to be given to both the content of communications and the way in which information is delivered. Clarity is essential.
6. Careful consideration should be given to policy decisions that place limits on access to respite services. For example, the level at which services are capitated clearly influences service use. Not all families benefit from the same dosage or amount of respite and it is possible for programs to be ineffective because the amount of service offered is insufficient.

# INTRODUCTION

**THIS PROJECT WAS SUPPORTED, IN PART, BY CONTRACT NUMBER NIH 16541-HHS, FROM THE ADMINISTRATION ON AGING, DEPARTMENT OF HEALTH AND HUMAN SERVICES, WASHINGTON, DC 20201. GRANTEES UNDERTAKING PROJECTS UNDER GOVERNMENT SPONSORSHIP ARE ENCOURAGED TO EXPRESS FREELY THEIR FINDINGS AND CONCLUSIONS. POINTS OF VIEW OR OPINIONS DO NOT, THEREFORE, NECESSARILY REPRESENT OFFICIAL ADMINISTRATION ON AGING POLICY.**

## INTRODUCTION

### PURPOSE

*This document reports findings from three related studies that extended the initial evaluation of the ADDGS program to obtain additional information about the patterns of use and delivery of respite services.* The studies focused on (1) factors related to client satisfaction with special attention to differences in cultural beliefs; (2) patterns of respite use over time; and (3) strategies used by providers to develop appropriate and successful respite services. Findings from the studies are potentially useful for providers and policy makers responsible for the allocation of limited resources and the development of respite programs.

### ALZHEIMER'S DEMONSTRATION PROGRAM

The Alzheimer's Demonstration Grant to States (ADDGS) Program was authorized through Sections 398, 399, and 399A of the Public Health Service (PHS) Act (P.L. 78-410), as amended by Public Law 101-157, Home Health Care and Alzheimer's Disease Amendments of 1990 and by Public Law 105-379, the Health Professions Education Partnerships Act of 1998. *The goal of this legislation was to expand support services for person's with Alzheimer's Disease and their caregivers.* Special attention has been given to reaching hard-to-serve and underserved populations. The demonstration was intended to assist grantees in planning, establishing, and operating demonstration programs in the following areas: (1) program development, (2) services delivery, and (3) information dissemination.

Fifteen grantees were selected through two rounds of competitive requests for proposals. In September of 1992, eleven states (*California, District of Columbia, Florida, Maine, Maryland, Michigan, Montana, Ohio, Oregon, Puerto Rico, South Carolina*) received a three-year Alzheimer's Demonstration Project grant award. In July of 1993, four additional states received a demonstration grant (*Georgia, Hawaii, North Carolina, and Washington*). The state demonstration projects were all extended through July 2000.

Unlike many federal programs, the Alzheimer's Demonstration has been characterized by great local diversity in design and implementation. Although every grantee has been responsible for the creation of respite services and outreach to hard-to-reach populations, each state (or territory) has developed and implemented a program of outreach and support services that is specific to the unique needs and resources of their citizens. A second hallmark of the project has been the development of cooperative partnerships among public and private organizations to integrate the new programs and services effectively into existing service environments.

### **WHAT IS RESPITE?**

Respite is a term used to refer to a wide range of services intended to give temporary relief to families caring for disabled members. This concept of care developed in the United States as a corollary of the early 1970s deinstitutionalization movement for developmentally disabled children and adults (Cohen, 1982). As families assumed the primary responsibility for the developmentally disabled, the need for temporary relief from their caregiving responsibilities created a demand for respite services. Recognition, in the United States, of the parallel need for relief of family members caring for frail and disabled elderly did not emerge until the mid 1980s when formal respite services were initially developed as demonstration projects.

While there is general consensus that respite means "an interval of temporary relief," there is almost no agreement as to the composition of the services that are to provide this relief. Respite programs have ranged from volunteers providing short periods of companionship to short stays in institutions. Services can be provided in a client's home (in-home services), in a group or institutional setting (out-of-home service), or in multiple settings (combination programs). Out-of-home services include foster homes, adult day-care centers, respite facilities, nursing homes, and hospitals. The only element common to these services is the intent to provide a period of relief for caregivers.

Within the three general types of respite settings, there are a number of possible variations depending upon the level of care, the types of activities available to participants, and the duration and frequency of respite episodes. Programs may vary along a continuum from low to high levels of care, and respite episodes may range from

short periods of a few hours to long stays of up to six weeks. Clients may be able to use services as frequently as once or twice a week or as infrequently as once or twice a year.

### ***In-home Care***

The most frequently requested and utilized form of respite service is in-home respite care provided for short periods, usually by a home health aide (Montgomery and Kosloski, 1994; Feinberg and Whitlach, 1998). A sitter/companion, homemaker, home health aide, or a nurse can provide in-home respite care. Some programs provide all of these levels of service while others may offer only companion or sitter services. Several public and private initiatives have encouraged the development of volunteer respite programs. These volunteer programs are usually confined to the companion level of care (Montgomery and Hatch, 1987). Most in-home programs provide services for a period of three to four hours, although some programs do offer more extended overnight or weekend services.

### ***Out-of-home Community Care***

The most common form of out-of-home respite is provided through adult day-care centers (Weissert et al., 1990; Montgomery, 1995). Usually respite care is offered in adult day-care centers on a regularly scheduled basis providing about four to six hours of care on each visit. Adult day care centers are best able to serve clients who need minimal assistance and, when they were initially developed, often did not enroll clients who were incontinent or who wandered (Montgomery and Kosloski, 1995). Additionally, some programs have been specifically developed for persons with Alzheimer's Disease or other related disorders (Lyman et al., 1993; Lindeman et al., 1991; Zawadski and Van Behren, 1990).

## **POTENTIAL BENEFITS OF RESPITE SERVICES**

Currently there is overwhelming consensus among families and service providers that respite services are the most desired and needed support for families caring for persons with Alzheimer's disease or other dementias. Many researchers suggest that respite care can relieve the burden of the caregiving situation and, perhaps, even allow families to continue to care for relatives who otherwise might have been institutionalized (Deimling, 1991; Van Werkhoven, 1991; Montgomery and Williams, *in press*).

### ***Benefits for Families***

Respite care is assumed to benefit both caregivers and the older persons for whom they provide care. The temporary relief from care tasks that respite services provide may reduce the level of stress that caregivers experience as a consequence of their care responsibilities. Indeed, adult day care has been seen to reduce care-related stress and increase psychological well-being of caregivers significantly (Zarit et al., 1998). Elders benefit indirectly from respite when the reduction in caregivers' stress and burden leads to enhanced quality of interactions between the caregiver and the care recipient. Elders attending day care centers also benefit directly from increased opportunities for socialization and stimulation.

### ***Reduced Long-term Care Costs***

Although, the belief that individual families benefit from respite programs has been one of the catalysts for the development of respite programs throughout the country, the major force driving the development of respite has been the general belief that respite programs may reduce the costs of long term care by reducing or delaying the need for more costly forms of care. Indirect support for this belief has been found in the fact that frail elders, who have in-home caregivers, are more likely to remain in the community than are those without such support, regardless of the elder's medical condition (Berman et al., 1987; Feinberg and Whitlatch, 1998). In addition, there is mounting evidence that the caregiver's capacities and health may be as important in predicting institutionalization as is the physical condition of the person receiving the care (McFall and Miller, 1992; Pruchno, Michaels, and Potashnik, 1990; Haug et al., 1999; Whitlatch et al., 1997). Direct support for the notion that respite may save long-term care costs has been relatively sparse. In fact, findings from early studies of respite programs failed to confirm delays in nursing home placement (Lawton et al., 1989; Montgomery and Borgatta, 1989). More recently, investigations that have used more appropriate methodologies for field studies of respite programs operating in communities have affirmed an empirical link between respite care and delayed placement (Montgomery and Kosloski, 1995; Zarit et al., 1998).

## **LIMITATIONS OF PREVIOUS RESEARCH**

To a large extent, any empirical evidence to demonstrate the psychological and monetary benefits of respite remains sparse and uneven because respite remains an

amorphous notion that has not been systematically studied. Previous studies have defined respite in different ways and focused on programs that offer very different services. In fact, some of the definitions of respite that have been used, ironically, did not even involve actual use of the service. Instead, respite was defined as merely having knowledge of, or access to, a particular service. For the most part, little attention has been given to the basic issues of dosage and timing of respite services. Most often, past evaluations have treated respite use as a dichotomous variable reflecting "use" versus "non-use" or even more problematic, "eligibility for use" versus "non-eligibility of use" (e.g. Lawton, Brody, and Saperstein, 1989; Montgomery and Borgatta, 1989).

Unlike pharmaceutical studies, which use rigid protocols to control the content and quantity of a treatment, respite as a treatment has varied widely in composition and quantity both among studies and within single studies. Insufficient attention has been given to describing service interventions or patterns of service use over time (Lawton, Brody and Saperstein, 1989; Montgomery and Borgatta, 1989). In the end, the relevance of past studies to real-life settings (i.e., their external validity) remains dubious. The question as to whether respite services ultimately reduce the cost of long-term care remains an important policy issue. Yet the question remains largely unanswered because little is truly known about how caregivers opt to use respite services when they are available. Despite growing evidence that respite services, indeed, do help families continue in their caregiving role for a longer period of time (see Montgomery and Kosloski, 1995), there is little systematic knowledge about long-term patterns of respite service use *in situ*.

It is also the case that the failure of researchers to make a definitive pronouncement about the efficacy of respite has done little to discourage practitioners and users of respite services. Respite programs have continued to proliferate. Practitioners have gone forward without waiting for explicit or even tacit approval from researchers. And, as a practical matter, answering the question of cost effectiveness does little to help community-based service providers to plan and implement their programs. They have a need for even more basic information about patterns of respite use. For example, in a real life setting, how much respite will a family use? Over what period of time do families use respite and at what level of intensity?

## PROJECT GOALS

These lingering questions about utilization patterns and the benefits of respite programs prompted the extended analyses of data from the AOA Alzheimer's Disease Demonstration Grant to States (ADDGS) program that are reported here. Specifically three studies were undertaken that capitalize on the unique qualities of the data that were gathered over a seven year period from September 1992 to October 1999.

The focus of Study One was to explore the links between clients' cultural characteristics and client satisfaction with respite services. The central purpose of the study was to identify differences among cultural groups in their beliefs about long term care and to determine whether these beliefs were linked with views about services offered through the ADDGS program. Data were gathered through interviews conducted with current caregivers. The underlying assumption of this study was that clients would be more likely to use those services that they deem appropriate and with which they were most satisfied. Knowledge of these factors could then be utilized by service providers to fine-tune their programs and maximize efficiency.

The primary purpose of Study Two was to identify and document long-term profiles of respite use among a diverse sample of families caring for elders with dementia. These profiles are potentially useful planning tools for policy makers and service providers responsible for implementing effective and efficient respite programs.

Study Three used a qualitative design to explore more fully the ethnic, geographic and familial contexts of service from the perspective of service providers. Data were gathered through interviews with key service delivery staff to identify successful strategies for addressing cultural and/or structural barriers to service use. The purpose was to provide a more detailed understanding of the issues confronting providers as they attempted to successfully develop and implement culturally appropriate support services for diverse populations.

# **ASSESSING CULTURAL AND STRUCTURAL BARRIERS TO SERVICE USE**

**CAREGIVER INTERVIEWS**

**STUDY ONE**

## EXECUTIVE SUMMARY

### STUDY ONE: ASSESSING CULTURAL AND STRUCTURAL BARRIERS TO SERVICE USE: CAREGIVER INTERVIEWS

#### OBJECTIVES

The central purpose of this study was to identify differences among cultural groups in their beliefs about family caregiving and their views of respite services offered through the ADDGS program. The links between culture and belief systems, perceptions of service accessibility, and client satisfaction were explored in detail. For this study, culture was defined in terms of three variables: ethnicity, family relationship, and geographic location. Each of these dimensions of diversity was examined as a factor potentially affecting clients' beliefs about caregiving and views of program services.

#### METHODS

Telephone interviews were conducted with a culturally diverse sample of 377 client caregivers from the ADDGS Program using a computer assisted telephone interview (CATI) system. Eleven measures caregivers' beliefs about family care responsibilities and nine measure of caregivers' perceptions of access and/or barriers to service use were examined. Analysis of variance was used to examine differences between cultural groups in belief systems. Multiple regression procedures were used to identify predictors of client satisfaction.

#### RESULTS

- Differences were observed between ethnic groups on 9 of the 11 measures of caregiver beliefs and attitudes about filial care and responsibility. In contrast, only one difference in beliefs was associated with geography and two differences were associated with the relationship of the caregiver to the elder.
  - Whites reported lower levels affection for the care recipients and less adherence to family values. Whites also expressed the highest level of guilt for using support services and were least likely to endorse the responsibility of government to provide support services.
  - Hispanic/Latinos reported the highest level of adherence to family values and the greatest respect for elders. As a group, Hispanics/Latinos were also most satisfied with the levels of social contact they currently experienced and the level of help they received.

- Black/African-Americans reported the highest levels of religiosity, the greatest strength of belief in God, and the highest levels of support from religious communities.
  - Spouses expressed greater affection for the care recipients and greater obligation to provide care than did children or other groups of caregivers. Spouses also reported significantly less family conflict.
  - Caregivers in urban areas reported greater respect for elders than those residing in rural areas.
  - Cultural differences in views of services were identified for only two aspects of service programs. Hispanic/Latino caregivers reported greater difficulty with communication relative to other groups. Notably, Whites reported the lowest levels for accessibility of services.
- The most satisfied **day care** clients were those who: (1) received high levels of support and comfort from their religious congregation; (2) had clear expectations regarding the program services; (3) judged the respite services to be appropriate for the client; and (4) perceived the “red tape” to be minimal.
- Clients of **in-home** services were most satisfied when they: (1) had clear expectations regarding the program services; (2) perceived the respite services to be accessible at the times they need it; and (3) judged the program staff to be friendly.

## IMPLICATIONS FOR PROVIDERS

The most significant findings from this study of client satisfaction are that differences in cultural beliefs do exist, but they are not important predictors of client satisfaction. Rather, four factors that are under the control of practitioners were found to be related to client satisfaction. These findings suggest that clients will be most satisfied when service providers:

- (1) convey to clients a clear understanding about what the respite program will and will not do in the way of providing care for the individual with AD;
- (2) reduce the amount of red tape associated with the program;
- (3) provide activities that caregivers believe to be appropriate for their family members; and
- (4) are flexible with the amount of service that is made available and the times at which it can be used.

## STUDY ONE:

### ASSESSING CULTURAL AND STRUCTURAL BARRIERS TO SERVICE USE— CAREGIVER INTERVIEWS

#### INTRODUCTION

As the population of the United States continues to become more diverse in age and ethnicity, there is growing concern for the care of disabled elderly persons. The provision of long-term care for elders with dementia, particularly those from traditionally underserved populations, poses complex problems at both the national and local levels.

Respite care is one type of family support service that helps the caregiver with the rigors of caregiving and may forestall institutional placement. However, a body of research suggests that uniform provision of respite service may not be appropriate for a population that is increasingly diverse. Instead, culturally dissimilar groups are likely to differ in their perceived need for, and evaluation of, respite services.

Cultural diversity is a broad rubric. Past research has identified patterns and preferences in the use of supportive services by caregivers of older adults that are associated with ethnicity, relationship to the care receiver (e.g., spouse vs. adult-child), and geographic location (urban vs. rural). Each of these factors identifies a different cultural grouping. Exactly how to interpret the effects of such cultural groupings on service use, however, remains uncertain because these factors each represent ascribed social statuses. Most researchers agree that when extraneous background factors that covary with ethnicity, relationship, or location are controlled (e.g., SES and need for service), any remaining differences in behavior can best be attributed to culturally-situated attitudes and beliefs related to membership in that cultural group (e.g., see Wolinsky et al., 1990). To date, the cultural attitudes and beliefs that might affect the use of community-based respite services have yet to receive any systematic attention.

*The goal of this study was to examine a broad array of attitudes and beliefs about caregiving and aspects of service delivery to determine (1) whether these factors are differentially associated with memberships in the various cultural groups and (2) the extent to which these culturally-based factors are related to satisfaction with services.*

## BACKGROUND

### Differences in Service Use Among Cultural Groups

Over the past decade, there has been a growing interest in the differential patterns of service use associated with cultural diversity. In general, findings from studies of health and social service use have been somewhat contradictory with regard to differences in service use among ethnic groups. There is evidence of greater use of support services among Blacks/African-Americans (Miner, 1995; Wallace et al., 1992), lower use of services among minorities (Greene and Monahan, 1984; Kemper, 1992); and no differences in formal service utilization by race (Hing and Bloom, 1990; Krout et al., 1990).

To the extent that cultural factors refer to the social norms governing elder care, however, the notion of culture necessarily refers to more than just ethnic differences (e.g., see Kosloski, Young and Montgomery, 1999, for a review). For instance, despite their greater workload, spouses of older patients are least likely among caregivers to seek and use formal services (Stoller and Cutler, 1992). This tendency is even more pronounced for wives, who tend to resist using outside support to a greater degree than do husbands (Stoller and Cutler, 1992; Tennstedt et al., 1989). Similarly, there is evidence that rural elderly, as a group, use fewer community-based support services than urban elders (Coward et al., 1990; Krout, 1994). In short, there are clear differences among cultural groups, broadly defined, in the likelihood of service use.

Explanations for these “cultural” differences in patterns of service use have taken two general forms (Miller, McFall and Campbell, 1994). On the one hand, race, relationship status of the caregiver, and rural status are ascribed social statuses that are associated with significant differences in the distribution of economic resources, greater levels of need, and differential access to services. Most of the past research undertaken to investigate cultural differences in service use has focused on these differences (e.g., see Angel et al., 1992; Schur et al., 1995; Tennstedt, Chang and Delgado, 1998). On the other hand, ascribed social statuses such as ethnicity, relationship status of the caregiver, and rural status are also proxy variables for a constellation of differing cultural beliefs, attitudes, and expectations for behavior. Every group has expectations for its members, and it has been shown that expectations, attitudes, and meaning differ across cultural groups (Nydegger, 1983). Currently, however, very little is known

about potential cultural differences of this sort. As Miller (1994) and her colleagues point out, there is a growing recognition that the association between culture and service use may reflect both differences in levels of need access to resources economic and differences in cultural beliefs (see also Belgrave, Wykle and Choi, 1991; Lockery, 1991; Mutran, 1985).

### **Culturally-based Attitudes and Beliefs about Services**

Exactly how cultural factors might influence views of services and ultimately service use is still a matter of some debate. Two plausible avenues of influence emerge from the caregiving literature. The first possibility is that being a member of a cultural group somehow affects the way that caregivers perceive the need for services. The second line of thinking suggests that the manner in which services are offered can be culturally insensitive and thereby create barriers to use in by some groups.

### ***Links between Perceptions of Need and Culturally-based Attitudes and Beliefs***

Any background characteristic that locates a caregiver within a homogenous cultural grouping of people can potentially affect the way in which that individual views the need for support services. In the case of ethnicity, normative expectations about care of family members and beliefs about familial responsibility have consistently been shown to differ among African-Americans, Asian Americans, and other groups (Gelfand and Barressi, 1987; Markides and Martin, 1983; Mutran, 1985; Stanford and Lockery, 1983). To the extent that these beliefs about family responsibility translate into different perceptions of need for services it makes sense that these beliefs will also influence the use of a supportive service, such as respite care. That is to say because a client's perceived need for that service can vary considerably from one observer to another, it makes a difference as to "who" is determining need (Andersen, 1995). The cultural characteristics of the decision maker are likely to affect the perceived level of "need." This link between ethnicity and perceived need is consistent with empirical findings from previous work of the authors that supports the notion that ethnicity moderates perceptions of need to affect service use (Kosloski, Montgomery and Karner, 1999).

The issue, with respect to the relationship of the caregiver to the individual with Alzheimer's disease, is similar. There appear to be clear differences in normative expectations toward care

of the elderly that are associated with different familial roles (Seelbach, 1978). For example, there is a considerable literature that documents differences between spouses and adult children in caregiving tasks and career patterns (Colerick and George, 1986; Montgomery and Datwyler, 1990). Spouses and children differ in their likelihood to seek and use support services (Kosloski and Montgomery, 1994). For example, if the wife of an impaired older person adheres to a normative belief that she is responsible for her husband's care, she may well experience serious guilt if she seeks the help of an outsider. Even if she does not feel guilty, other persons in her circle of friends or family may make a negative judgment about her role performance. A daughter who has her own family to care for and who is employed outside of the home may well experience stress if she were to care for her mother as well, but is less likely to experience negative social consequences if she were to seek outside help than would a spouse caregiver. Not surprisingly, spouses who are caregivers appear to make different determinations of need for support services than do adult-children (Kosloski and Montgomery, 1994).

Finally, the notion of a common culture with shared belief systems can be extended to include urban versus rural elders as well. A commonly held vision of rural life is that of a healthy, vigorous older couple living on a prosperous, immaculately tended homestead surrounded by a tight, intergenerational network of family and friends. In actuality, "there is very little evidence to support the popular, and widely accepted notion that rural elders have family networks that are stronger and more able to respond to their needs than urban elders" (Coward and Dwyer, 1991, p. 24). Nonetheless, to the extent that rural caregivers subscribe to this stereotype, they are less likely to use outside services.

### ***Links between Cultural Beliefs and Perceptions of Service***

Perceptions of services may also vary among cultural groups depending upon the manner in which the services are actually delivered. To date, within the Gerontological literature differences in client perceptions about access and barriers have been addressed almost exclusively with a focus on ethnic differences (see also Yeatts, Crow, and Folts, 1992, for a more comprehensive overview of the issues involved). A much broader literature exists in the area of medical service use where the competition for clients is more intense, and the viability of a service provider is more closely linked to how the service is viewed by those who utilize its services. In such arenas, client satisfaction with services, and the interpersonal relationships

between providers and service users, are of central concern to service providers (Morishita et al., 1998; Sanders et al., 1998). From this perspective, the factors related to client satisfaction are important, regardless of ethnicity, relationship of the caregiver to the patient, or geographic location.

To the extent that the cultural factors are related to clients' expectations for services and client satisfaction with various aspects of service delivery, service providers can use this information to tailor their services to their specific clientele. In this manner providers can increase client satisfaction and solidify their customer base (Ware and Davies, 1983). The emphasis that medical providers have placed on client satisfaction is now emerging among providers of services for older adults (Geron et al., 2000; Simmons and Schnelle, 1999). For example, the quality of communication has consistently been found to an important determinant of client satisfaction (e.g., Bordy et al., 1989; Hall et al., 1988). Expectations for services are also important. Specifically, discrepancies between what clients expect to receive from a service and what they actually receive can significantly affect clients' evaluations of services (Falvo and Smith, 1983; Ross et al., 1995). In a similar manner, friendliness and interaction styles can affect satisfaction with service encounters (Greene et al., 1994). Not surprisingly, the extent to which the client trusts the service provider has been found to be a major determinant of satisfaction in health care delivery (Safran et al, 1998). Given the fragile condition of AD patients and their extreme dependence on their caregivers, trust is likely to emerge as an important factor in respite use as well. In addition to the foregoing factors, Yeatts and his colleagues (Yeatts, Crow, and Fouts, 1992) note the importance of factors such as service availability, attractiveness of the services or activities, and shared perspectives on care. Each of these latter factors has been shown to be related to both client outcomes such as satisfaction and cultural factors.

### **Conceptual Model**

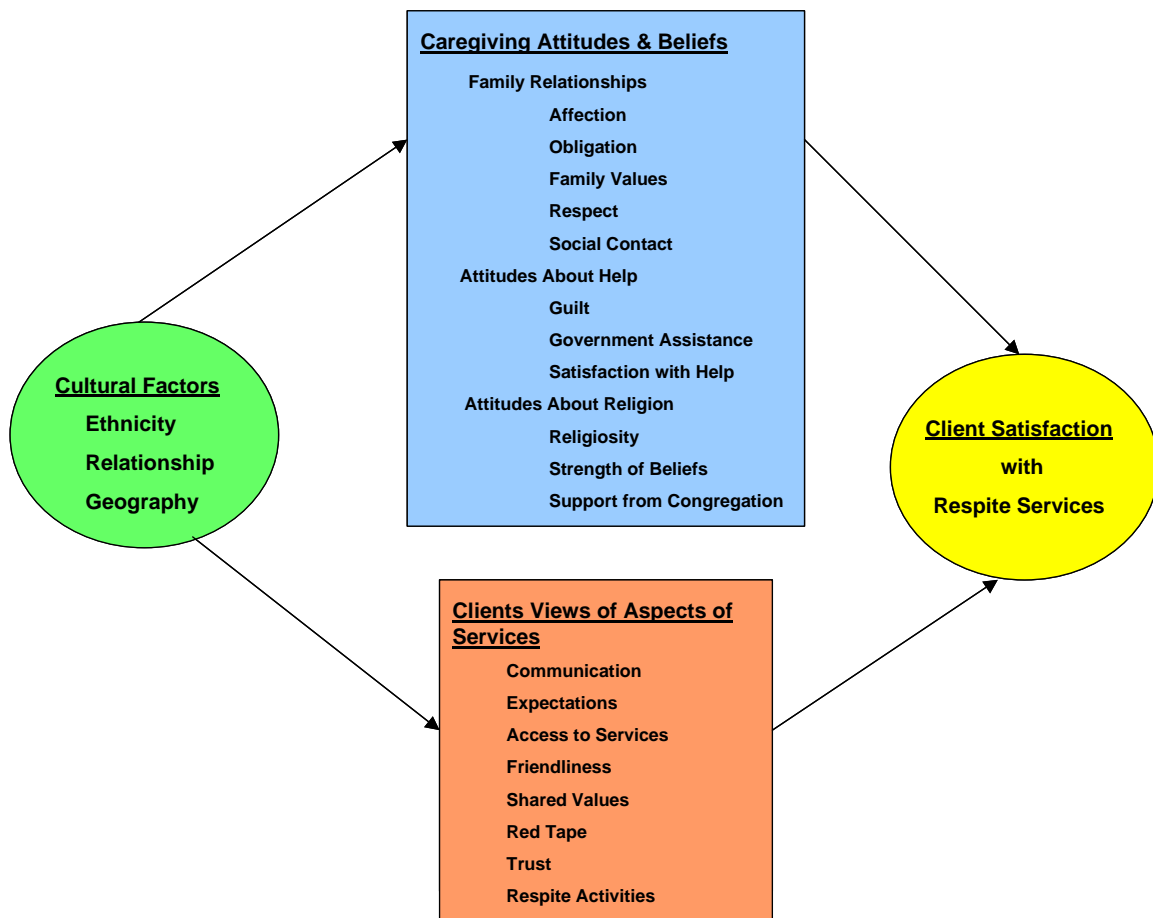
The two mechanisms by which cultural factors could potentially influence client satisfaction are depicted in Figure 1.1. As shown, the three types of cultural factors i.e., by ethnicity, relationship of the caregiver to the patient, or geographic location (urban vs. rural) can be viewed as factors influencing both caregiving attitudes and beliefs and perceptions about services. Caregiving attitudes and beliefs are grouped, in the blue box, under three headings:

(1) Family Relationships which include affection for the elder, perceived obligation to care, family values, respect for elders, and desired frequency of social contact; (2) Attitudes about Help including guilt at respite use, attitudes toward government assistance, and satisfaction with help with caregiving; and (3) Attitudes about Religion which include religiosity, strength of beliefs, and support provided by religious congregation. Each of these attitudes and/or beliefs can differ. In turn, each of the attitudes and/or beliefs can affect the client's satisfaction with respite services.

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**Figure 1.1 Assessing Cultural and Structural Barriers to Service Use**

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The relationship between cultural factors and aspects of service delivery is also illustrated in Figure 1.1. Eight different aspects of service delivery, in the orange box, that are likely to affect clients' perceptions of respite services are investigated in the present study: communication, expectations, access to services, friendliness, shared values, red tape, trust, and appropriate activities. Consistent with the previous research from other service domains, these eight factors are also expected to influence clients' satisfaction with respite services.

## **METHODS**

### **Purpose of Study**

Study One was undertaken to evaluate each of the hypothesized relationships shown in Figure 1.1. Specifically the goal of the study was to (1) to evaluate possible differences in culturally-based attitudes and beliefs concerning the use of support services – particularly the use of respite services – and (2) to determine whether these differences are related to important outcomes of service use – specifically, client satisfaction with services.

### **Overview**

Interviews were conducted with a culturally diverse sample of 377 family caregivers participating in the ADDGS program. Of these, 168 were white, 116 were African-American, and 91 were Hispanic. Approximately 35% were spouses and 45% resided in rural areas. Attitudes and beliefs about caregiving were assessed using 12 factors grouped under three broad headings dealing with Family Relationships (e.g., felt obligation to care), Attitudes toward Outside Help (e.g., guilt from using from services), and Attitudes about Religion (e.g., support from religious beliefs). Eight clients views of aspects of services were also examined including factors such as communication difficulties, access to services, and staff friendliness.

### **Sample Selection**

Initially 1138 caregivers were identified from the ADDGS service records of eight states (California, Washington D.C., Florida, Maine, Michigan, North Carolina, South Carolina, Washington) as potential subjects for the study. Each state was selected based upon the criteria that it served specific target populations (Blacks/African-Americans, Hispanics/Latinos, and/or rural) and had consistently provided reliable data over the course of the demonstration.

The initial sample pool included all White, Black/African-American, and Hispanic/Latino caregivers who met three criteria: (1) The family had utilized in-home respite or adult day care made available through the Alzheimer's Demonstration; (2) Complete demographic information was available for the caregiver and elder from project records; and (3) Current street address and telephone contact information were available for the caregiver.

Letters explaining the study and the benefits of participation were sent to each of the 1138 caregivers in the initial subject pool (see Appendix 1A). A set of response cards was also enclosed to aid participation in the interview. Approximately twelve days after the mailing of the initial letter, a trained interviewer placed a call to the caregiver to set an acceptable time for the interview to be conducted. If the caregiver was not reached by telephone on the initial attempt, up to 15 repeat attempts were made to contact the subject.

Of the original sample pool, 422 caregivers (37%) were ineligible for the study for a variety of reasons. Among those, 335 subjects (29% of original sample) were former caregivers of elders who were deceased or institutionally placed. Forty five (4%) caregivers had not used respite services within the last year. In 20 (2%) of the cases, the person who formerly provided care no longer provided assistance to the elder. Three of the elders did not have a caregiver, and eight of the caregivers were paid professionals. Eleven (1%) of the caregivers were excluded from the study because they had poor or no recollection of having used demonstration services. For some, this was due to the fact that they had signed up for services, but had not yet started using them. For others, their pattern of use had been infrequent, or had lapsed for such a period of time that they could not formulate an opinion regarding their satisfaction.

This left an eligible sample of 716 caregivers. Of these, inaccurate or outdated contact information that could not be updated by state officials precluded contact with 155 caregivers, reducing the sample to 561. Of these, 91 persons could not be contacted after 15 attempts. An additional 100 members of the original pool of subjects refused to participate despite their eligibility. This group included non-current caregivers that declined to discuss their past caregiving role and current caregivers who refused for other reasons. Some caregivers, particularly spouses, were ill or suffered from memory problems themselves due to advancing age. Others, especially adult children, declared themselves too busy to participate due to work

or other familial obligations. Full interviews were completed with 370 caregivers invited to participate, or 79% of the valid sample who could be contacted. This final sample included current caregivers, and non-current caregivers who had used respite services within the twelve months prior to the interview. The final status of the potential subjects is shown in Table 1.1.

**TABLE 1.1. DISTRIBUTION OF SAMPLE BY INTERVIEW COMPLETION**

	<b>N</b>	<b>%</b>		<b>N</b>	<b>%</b>
<b>Initial Sample</b>	1138	100.0%	<b>Suppl. Sample</b>	14	100.0%
<b>Interview Complete</b>	370	32.5%		7	50.0%
<b>Deemed Ineligible</b>	422	37.1%		2	14.3%
Deceased/Placed	335	29.4%		0	0.0%
Non-Current Users	45	4.0%		1	7.1%
No Longer Caregiver	20	1.8%		0	0.0%
Client Self-Care	3	0.3%		0	0.0%
Paid Caremanager	8	0.7%		0	0.0%
No Recollection of Use	11	1.0%		1	7.1%
<b>Unable to Contact</b>	246	21.6%		5	35.7%
Wrong Contact Information	155	13.6%		1	7.1%
15 Attempts Unsuccessful	91	8.0%		4	28.6%
<b>Refused</b>	100	8.8%		0	0.0%
<b>Total Sample</b>	1152	100.0%	<b>Total Interviewed</b>	377	32.7%

Since the number of Hispanic/Latino caregivers was quite small, an attempt was made to supplement the sample size by adding 14 Hispanic/Latino caregivers from the state of California who had used demonstration respite services, but had not been subsidized with demonstration funds. With the addition of these 14 subjects, seven of which completed the interview, the total sample size for the study was 377. Demographic information was collected from the supplemental sample of Hispanic/Latino caregivers at the time of interview. The distribution of the sample by state and ethnicity is depicted in Table 1.2.

### **Data Collection**

Data pertaining to the demographic characteristics of caregivers and elders were taken from the information collected at the point of intake for each family participating in the ADDGS program. Additional data pertaining to caregivers' beliefs and attitudes and their views concerning aspects of service delivery were obtained through structured telephone interviews. Specifically, in the

fall of 1999, twenty minute telephone interviews were conducted with 377 client caregivers from the ADDGS. Caregivers were asked about their experiences with demonstration services, their satisfaction with services, their views on caregiving, and their experiences providing care. Interviews were conducted using a computer assisted telephone interview (CATI) system that allowed for simultaneous data entry of the responses during the interview process.

**TABLE 1.2. DISTRIBUTION OF SAMPLE BY STATE AND RACE (N=377)**

	White		Black/Afr-American		Hisp/Latino		All Groups	
	N	%	N	%	N	%	N	%
<b>California</b>	5	3.0%	0	0.0%	38	40.9%	43	11.4%
<b>Washington D.C.</b>	1	0.6%	25	21.6%	3	3.2%	29	7.7%
<b>Florida</b>	18	10.7%	31	26.7%	30	32.3%	79	21.0%
<b>Maine</b>	48	28.6%	0	0.0%	0	0.0%	48	12.7%
<b>Michigan</b>	33	19.6%	15	12.9%	1	1.1%	49	13.0%
<b>North Carolina</b>	18	10.7%	19	16.4%	2	2.2%	39	10.3%
<b>South Carolina</b>	44	26.2%	24	20.7%	0	0.0%	68	18.0%
<b>Washington</b>	1	0.6%	2	1.7%	19	20.4%	22	5.8%
<b>Total</b>	168	44.6%	116	30.8%	93	24.7%	377	100.0%

### Measures

Items included in the questionnaire (see Appendix 1B) were carefully screened prior to inclusion. Some items were included because they provided important information about the demographic and background characteristics of the participants. Other items were included because they were intended to measure client beliefs and attitudes about family care responsibilities and the appropriateness of using formal support services. Whereas a single item can usually be used to assess respondent demographic characteristics reliably (e.g., gender or ethnicity), multiple items are generally required to reliably assess concepts such as caregiver beliefs, accessibility of services, and client satisfaction. Consequently, multiple items from the interview instrument were used to create measures of the key concepts related to

caregiver beliefs about family care, accessibility of services, and satisfaction with services (see Appendix 1C).

The first phase of data analysis entailed the development of reliable measures for each of the key concepts using items included in the interview schedule. This evaluation involved several steps. First, the pattern of frequencies of responses was examined for each item. Questions were not asked of subgroups of respondents when not applicable. As a result of these “skip patterns,” different sample sizes were obtained for different items in the interview schedule. In other cases, respondents may have been reluctant to respond to a particular question (e.g., questions about income). Decisions about how to handle such “missing data” were made in the context of the particular purpose underlying each analysis.

To increase reliability, several items were generally hypothesized to tap a common latent variable or “factor.” Thus, the second step in the item analysis involved submitting the relevant items to a common factor analysis. Although there are many different techniques subsumed under the broad rubric of “factor analysis”, when the questionnaire items work as hypothesized (i.e., there is a clear structure to the data), they all produce essentially the same result. The main issue is primarily a statistical one—how to construct the correlation matrix to be analyzed. The general rule in this study was to use a form of principal axis factoring (i.e., communality estimates are placed in the diagonal rather than unities) with an orthogonal rotation. (Interested readers should consult Nunnally, 1978; Widaman, 1993.)

The third step in the item analysis was to estimate the reliability of the measure created by the selected multiple items. Cronbach’s alpha was used to estimate the internal consistency of each measure. The alpha coefficient can range from 0 to 1, with higher scores desirable.

### ***Measures of Demographic and Background Variables***

Eight variables were included as measures of demographic and background characteristics of elders. These demographics included *gender, marital status, income, age, geographic location, living arrangement, total residents in household, and number of services used prior to entry* (see Appendix 1B).

Four additional variables were included as measures of elders' functional status. These measures included *diagnostic status*, *problem behaviors*, *ADL level*, and *IADL level*.

Demographic characteristics of caregivers were assessed either at the time of intake or interview. Measures drawn from intake information included *gender*, *age*, *marital status*, *education*, *employment*, *income*, *length of caregiving before program entry*, and *driving distance from elder*. Caregivers' *relationship to elder*, *number of persons in household*, *help provided by elder*, and *availability of a back-up caregiver* were collected as part of the interview.

Four characteristics of caregivers' health and well-being rounded out the demographic and background characteristics. The interview schedule included items about *life satisfaction*, *physical health*, and *detriment to work while caregiving*. A measure of the degree of *depressive symptomology* was also included in the interview.

### ***Measures of Caregiver Beliefs***

Eleven composite variables were constructed to measure aspects of caregivers' beliefs about aging and responsibilities for care. These measures included *affection for elder*, *obligation to care*, *family values*, *respect for elders*, *desired frequency of social contact*, *guilt at respite use*, *attitudes toward government assistance*, *satisfaction with help with caregiving*, *religiosity*, *strength of beliefs*, and *support provided by religious congregation*. The individual items used to create the composite measures are listed in Table 1.3 along with the estimated reliability of each measure.

### ***Measures of Access/Barriers***

Nine composite variables were constructed to measure caregivers' perceptions of access and/or barriers to service use. These included *client satisfaction*, *communication difficulties*, *clear expectations*, *access to services*, *friendliness of staff*, *shared values with staff*, *institutional barriers*, *trust in staff*, and *appropriateness of activities*. Individual items for each of these measures and the estimated reliability for each measure are listed in Table 1.4.

**TABLE 1.3. MEASURES OF CAREGIVER BELIEFS AND ATTITUDES**

<b>Variable</b>	<b>Items</b>	<b>Reliability</b>
<b>FAMILY RELATIONSHIPS</b>		
<b>Affection for Elder<sup>A</sup></b>	<ol style="list-style-type: none"> <li>1. I am extremely close to my [relative].</li> <li>2. I have great affection for my [relative].</li> <li>3. I have a strong attachment to my [relative].</li> <li>4. I am completely devoted to my [relative].</li> <li>5. I love my [relative] very much.</li> <li>6. I genuinely like my [relative].</li> </ol>	0.89
<b>Obligation to Care<sup>A</sup></b>	<ol style="list-style-type: none"> <li>1. It is my duty to care for my [relative].</li> <li>2. I personally must protect my [relative]'s interests.</li> <li>3. I feel I have to assume caregiving tasks for my [relative].</li> <li>4. I am morally bound to care for my [relative].</li> <li>5. It is my obligation to help my [relative].</li> <li>6. I am responsible for my [relative].</li> </ol>	0.81
<b>Family Values<sup>B</sup></b>	<ol style="list-style-type: none"> <li>1. When someone has problems, s/he can count on help from his/her relatives.</li> <li>2. People should seek the advice of older relatives in important matters.</li> <li>3. A person should share his/her home with uncles, aunts, or first cousins if they are in need.</li> <li>4. It is still important to obey the wishes of parents/older relatives.</li> <li>5. True wisdom comes with age.</li> <li>6. If a relative told you he is in financial difficulty, you would help as much as you could.</li> <li>7. One can count on help from relatives to solve most problems.</li> <li>8. Aging parents should live with their relatives.</li> </ol>	0.74
<b>Respect for Elders<sup>B</sup></b>	<ol style="list-style-type: none"> <li>1. The oldest person in the family should have final say in family decisions.</li> <li>2. Certain positions of responsibility should be given only to older persons.</li> </ol>	0.70
<b>Desired Frequency of Social Contacts<sup>D</sup></b>	<ol style="list-style-type: none"> <li>1. Would you like to see or talk to your relatives more often, less often, or as often as you do now?</li> <li>2. Would you like to see or talk to your friends more often, less often, or as often as you do now?</li> </ol>	0.60

**TABLE 1.3. MEASURES OF CAREGIVER BELIEFS AND ATTITUDES**

(continued)

Variable	Items	Reliability
<b>ATTITUDES REGARDING HELP</b>		
<b>Guilt at Respite Use<sup>B</sup></b>	1. My family thinks less of me if I use respite for my [relative]'s care. 2. My family doesn't think we should use respite services for our [relative]. 3. People outside my family would think less of me if they knew that I used respite services.	0.68
<b>Attitudes toward<sup>B</sup> Government Assistance</b>	1. The government should provide more money for respite services. 2. The government should help families care for persons at home.	0.76
<b>Satisfaction with Help<sup>C</sup> with Caregiving</b>	1. How satisfied are you with the amount of help you receive from others in assisting your [relative]? 2. How satisfied are you with the amount of emotional support you have received from others in the past 6 months?	0.71
<b>ATTITUDES REGARDING RELIGION</b>		
<b>Religiosity<sup>E</sup></b>	1. Religion is a source of great strength and comfort to you. 2. You try hard to carry your religious beliefs over into all your other dealings in life. 3. You consider yourself to be a very spiritual person.	0.84
<b>Strength of Beliefs<sup>F</sup></b>	1. You look to God for strength, support, and guidance in crises. 2. You try to find the lesson from God in crises.	0.91
<b>Support from Religious<sup>G,H</sup> Congregation</b>	1. How often do people in your congregation listen to you talk about your private problems and concerns? <sup>G</sup> 2. How often do the people in your congregation express interest and concern in your well-being? <sup>G</sup> 3. If you had a problem or were faced with a difficult situation, how much comfort would the people in your congregation be willing to give you? <sup>H</sup>	0.77
<b>Response Sets:</b>		
<b>Response Set A</b> = (1) not at all true; (2) a little true; (3) somewhat true; (4) quite a lot true; (5) completely true		
<b>Response Set B</b> = (1) not at all true; (2) a little true; (3) somewhat true; (4) quite a lot true; (5) extremely true		
<b>Response Set C</b> = (1) very dissatisfied; (2) dissatisfied; (3) somewhat satisfied; (4) satisfied; (5) very satisfied		
<b>Response Set D</b> = (1) more often; (2) less often; (3) as often as now		
<b>Response Set E</b> = (1) strongly disagree; (2) disagree; (3) agree; (4) strongly agree		
<b>Response Set F</b> = (1) not at all; (2) somewhat; (3) quite a bit; (4) a great deal		
<b>Response Set G</b> = (1) never; (2) once in awhile; (3) fairly often; (4) very often		
<b>Response Set H</b> = (1) none; (2) a little; (3) some; (4) a great deal		

## **Sample Characteristics**

### ***Elder Characteristics***

Demographic characteristics are shown separately for White, Black/African-American, and Hispanic/Latino elders in Table 1.5. The majority of elders in all ethnic groups were females with an average age of approximately 79 years. Black/African-American elders differed from the other groups in their marital status. Just over half (54.2%) of the White elders were married; 41.7% were widowed. In contrast, only 29.3% of Black/African-Americans and 41.9% of Hispanic/Latino elders were married. Widows or widowers comprised 56.9% of the Black/African American sample and 46.2% of the Hispanic/Latino sample.

Elders of all ethnic groups were concentrated in the lower end of the income spectrum, but differences existed among the three ethnic groups. White elders were more likely than Blacks/African-Americans to have average incomes that exceeded \$15,000. Hispanic/Latino elders were considerably less likely than Black/African-American elders to occupy higher income strata.

Group differences were also observed in geographic location. A greater proportion of Hispanic/Latino elders resided in urban or suburban areas than did Black or White elders. This difference likely reflects the focus of the ADDGS grant on serving urban minority and rural caregivers, and highlights the fact that geographic location and minority status are not independent of one another. Living arrangements varied among the three groups. While only a small proportion of elders in any of the groups lived alone, Hispanic/Latino elders (8%) were least likely, and Black/African-American elders (14%) were most likely to live alone. A larger segment of Hispanic/Latino elders resided in households of four or more persons than did elders of other ethnicities. There were differences among groups in the relationship of the elder to his/her housemates as well. A greater proportion of Whites (54%) resided with a spouse than was true for either Black/African-American (34%) or Hispanic/Latino (36%) elders. Hispanic/Latino elders were more likely than Whites to reside with an adult child or child-in-law. Black/African-American elders (11%) were more likely than members of the other two ethnic groups to live with a person other than a spouse or child, which is a reflection of the lower rates of marriage shown in the Black/African-American elder population (29%). With more than half (55%) of the Hispanic/Latino elders reporting no use of support services prior the demonstration

services, they were less likely than other groups to have used support services prior to their entry into the demonstration.

Variations in elders' functional status showed similar patterns, as illustrated in Table 1.6. The mean ADL and IADL scores for Black/African-American elders were somewhat lower than those of White and Hispanic/Latino elders, indicating a higher functional level. Similarly, Black/African-American elders in this sample also differed from the other groups in the prevalence of

**TABLE 1.4. MEASURES OF CLIENTS' VIEWS OF SERVICES**

<b>Variable</b>	<b>Items</b>	<b>Reliability</b>
<b>Client Satisfaction<sup>B</sup></b>	1. In general, I am satisfied with the care my [relative] receives. 2. I am satisfied with the respite program services. 3. I would recommend this service to others.	0.84
<b>Communication<sup>B,I,J</sup> Difficulties</b>	1. When the respite workers discuss my [relative]'s health and care needs with me, they use words I understand. <sup>B</sup> 2. How easy is it for you to talk with the respite workers? <sup>I</sup> 3. When talking with the respite worker, how difficult is it to explain what help you want? <sup>I</sup> 4. Workers at the respite program speak your language. <sup>J</sup>	0.59
<b>Clear Expectations<sup>B</sup></b>	1. The information that I received about the program gave me a clear idea of what to expect from the workers. 2. It was made clear to me exactly what the respite worker would and would not do. 3. The service workers from the respite program understand how I think.	0.65
<b>Access to Services<sup>B</sup></b>	1. Respite is readily available when I need it. 2. It is easy to increase the amount of service we receive. 3. We can get the amount of respite care that we need.	0.76
<b>Friendliness of Staff<sup>J,B</sup></b> (1-2)1 = never true - 5 = always true (3-4)1 = not at all true - 5 = extremely true	1. The workers are welcoming and friendly to you. <sup>J</sup> 2. The workers are disrespectful. <sup>J</sup> 3. Program staff speak you my [relative] and myself in a considerate manner. <sup>B</sup> 4. The program staff members are respectful of my [relative]'s cultural heritage. <sup>B</sup>	0.65

**TABLE 1.4. MEASURES OF CLIENTS' VIEWS OF SERVICES**

(continued)

Variable	Items	Reliability
<b>Shared Values<sup>B</sup> with Staff</b>	<ol style="list-style-type: none"> <li>1. The program workers take into account my [relative]'s cultural preferences.</li> <li>2. The workers share my views about how family members should treat each other.</li> <li>3. The respite workers take care of my [relative] the way I want them to.</li> </ol>	0.80
<b>Redtape<sup>B,I,J</sup></b> (1-5) 1 = never true - 5 = always true  (6-7) 1 = not at all - 5 = extremely  (8-11) 1 = not at all true - 5 = extremely true	<ol style="list-style-type: none"> <li>1. You have to wait too long in the program office when you need to see someone.<sup>J</sup></li> <li>2. Your [relative] complains about using the services.<sup>J</sup></li> <li>3. It is difficult to get the respite services your [relative] needs because you do not know where to find them.<sup>J</sup></li> <li>4. You have to wait too long to get an appointment to get the services you need.<sup>J</sup></li> <li>5. You lose pay from work when you use the respite services.<sup>J</sup></li> <li>6. How reasonable is the service fee for your family budget?<sup>I</sup></li> <li>7. How convenient were the times respite was offered?<sup>I</sup></li> <li>8. The application process for the program is very difficult.<sup>B</sup></li> <li>9. It takes a great deal of effort for me to use this program.<sup>B</sup></li> <li>10. It is easy to decrease the amount of service we receive.<sup>B</sup></li> <li>11. It is difficult to change the times that respite is available.<sup>B</sup></li> </ol>	0.59
<b>Trust in Staff<sup>B</sup><sub>1</sub></b>	<ol style="list-style-type: none"> <li>1. I trust program staff to be alone with my [relative].</li> <li>2. I trust program workers to be in my home or with my [relative] when I am not there.</li> <li>3. The program workers are careful with my possessions.</li> <li>4. Program staff are respectful of my home and my things.</li> </ol>	0.82
<b>Appropriateness of<sup>B</sup><sub>2</sub> Activities</b>	<ol style="list-style-type: none"> <li>1. The respite workers plan activities that are appropriate for my [relative].</li> <li>2. The program staff serve familiar meals for my [relative].</li> <li>3. My [relative] is familiar with the music/songs that the respite workers choose.</li> </ol>	0.61

<sub>1</sub> This question was only asked of caregivers who used in-home respite.

<sub>2</sub> This question was only asked of caregivers who used day care / group respite.

**Response Sets:**

**Response Set B** = (1) not at all true; (2) a little true; (3) somewhat true; (4) quite a lot true; (5) extremely true

**Response Set I** = (1) not at all; (2) a little; (3) somewhat; (4) quite a lot; (5) extremely

**Response Set J** = (1) never true; (2) rarely true; (3) sometimes true; (4) frequently true; (5) always true

problematic behaviors, which were measured at the time of intake with a 15-item inventory (described in detail in Appendix 1C). Black/African-American caregivers reported significantly fewer problem behaviors, indicating less impairment. The mean problem behavior score for Hispanic/Latino caregivers was 15.4, which was higher than that of both White caregivers (13.5) and Black/African-American caregivers (10.8).

**TABLE 1.5. DEMOGRAPHIC CHARACTERISTICS OF ELDERS BY RACE (N=377)**

	<b>All Groups</b>		<b>White</b>		<b>Black/African-American</b>		<b>Hispanic/Latino</b>	
	<b>377</b>	<b>100%</b>	<b>168</b>	<b>44.6%</b>	<b>116</b>	<b>30.8%</b>	<b>93</b>	<b>24.7%</b>
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
<b>Gender</b>								
Male	111	29.4%	55	32.7%	29	25.0%	27	29.0%
Female	266	70.6%	113	67.3%	87	75.0%	66	71.0%
<b>*Marital Status</b>								
Single	18	4.8%	3	1.8%	5	4.3%	10	10.8%
Married	165	43.8%	91	54.2%	34	29.3%	39	41.9%
Widowed	177	46.9%	70	41.7%	66	56.9%	43	46.2%
Other	17	4.5%	4	2.4%	11	9.5%	1	1.1%
<b>*Average Income</b>								
Under \$5,000	150	39.8%	79	47.0%	35	30.2%	33	35.5%
\$5,000 - \$15,000	194	51.5%	77	45.8%	77	66.4%	44	47.3%
\$15,001 - \$30,000	6	1.6%	5	3.0%	1	0.9%	0	0.0%
\$30,001 - \$50,000	1	0.3%	0	0.0%	0	0.0%	0	0.0%
Over \$50,000	0	0.0%	1	0.6%	0	0.0%	0	0.0%
Unknown	26	6.9%	6	3.6%	3	2.6%	16	17.2%
<b>Mean age</b>	78.9		79.7		78.2		78.2	
<b>*Geographic Location</b>								
Urban	191	50.7%	51	30.4%	70	60.3%	70	75.3%
Rural	153	40.6%	106	63.1%	39	33.6%	8	8.6%
Unknown	33	8.7%	11	6.5%	7	6.0%	15	16.1%
<b>*Living Arrangement</b>								
Live Alone	40	10.6%	19	11.3%	16	13.8%	7	7.5%
Live with Spouse	158	41.9%	90	53.6%	39	33.6%	33	35.5%
Live with Children	141	37.4%	49	29.2%	48	41.4%	39	42.0%
Other	29	7.7%	10	6.0%	13	11.2%	5	5.4%
Unknown	9	2.4%	0	0.0%	0	0.0%	9	9.7%

**TABLE 1.5. DEMOGRAPHIC CHARACTERISTICS OF ELDERS BY RACE (N=377)--Continued**

	All Groups		White		Black/African-American		Hispanic/Latino	
	377	100%	168	44.6%	116	30.8%	93	24.7%
	N	%	N	%	N	%	N	%
<b>*Total Number in Household</b>								
Live Alone	40	10.6%	19	11.3%	16	13.8%	7	7.5%
Elder + 1 other	166	44.0%	88	52.4%	46	39.7%	30	32.5%
Elder + 2 others	85	22.5%	42	25.0%	28	24.1%	17	18.3%
Elder + 3 or more	75	19.9%	18	10.7%	26	22.4%	29	31.2%
Other/Unknown	11	2.9%	1	0.6%	0	0.0%	10	10.8%
<b>*Number of Services Used Prior to Entry</b>								
0	150	39.8%	53	31.5%	43	37.1%	51	54.8%
1 - 2	198	52.5%	97	57.7%	64	55.2%	40	43.0%
3 or more	29	7.7%	18	10.7%	9	7.8%	2	2.2%

\* Significant differences between ethnic groups at  $p \leq .05$

**TABLE 1.6. ELDER FUNCTIONAL STATUS BY ETHNICITY (N=377)**

	All Groups		White		Black/African-American		Hispanic/Latino	
	377	100%	168	44.6%	116	30.8%	93	24.7%
	N	%	N	%	N	%	N	%
<b>Alzheimer's Disease</b>								
Suspected	60	15.9%	21	12.5%	17	14.7%	25	26.9%
Diagnosed	274	72.7%	133	79.2%	92	79.3%	45	48.4%
Other	31	8.2%	13	7.7%	6	5.2%	13	14.0%
Unknown	12	3.2%	1	0.6%	1	0.9%	10	10.8%
<b>*Problem Behavior</b>								
Mean Score (0 - 45)	13.2		13.5		10.8		15.4	
<b>Functional Level</b>								
Mean ADL (0 - 10)	3.8		4.1		3.4		4.0	
Mean IADL (0 - 16)	12.0		12.3		11.7		12.0	

\* Statistically significant differences between ethnic groups at  $p \leq .05$

Finally, there were differences between the Hispanic/Latino group and the other two groups in the proportion of elders who were diagnosed with Alzheimer's disease. Among White elders, 79.2% were diagnosed with AD and another 12.5% were suspected to have the disease. A similar pattern was observed for Black/African-Americans, with 79.3% having an AD diagnosis and 14.7% reporting that AD was suspected. In contrast, only 48% of the Hispanic/Latino group

were diagnosed with AD, with 27% reporting the disease to be suspected. The diagnostic status was unknown for almost 11% of Hispanic/Latinos sample, in contrast to less than 1% among the other two groups.

### ***Caregiver Characteristics***

Significant differences in demographic characteristics were also observed among the ethnic groups, with the exception of gender and age of the caregivers. As shown in Table 1.7, almost three-quarters (72%) of the caregivers in all of the ethnic groups were female and the mean age was approximately 61 years. Similar to the patterns observed for the elders, a smaller proportion of the Black/African-American caregivers (51%) than of the other groups was married. Conversely, a greater proportion of the Black/African-American caregivers was single or divorced (34%).

Levels of education, employment, and income also differed by ethnicity. White caregivers had higher levels of education than did Black/African-Americans, who were in turn more educated than the Hispanic/Latino caregivers of the sample. In regard to employment, a smaller proportion of Hispanic/Latino caregivers were retired (26%), and a larger segment remained employed full-time (27%), compared to the other two groups. The differences among the three groups in income levels mirrored those among education levels. White caregivers earned more than Black/African-Americans, who earned more than Hispanics/Latinos.

Patterns of caregiving and living arrangements differed by ethnicity as well. Hispanic/Latino caregivers provided care slightly longer than Black/African-American caregivers before enrolling in the ADDGS demonstration. For all groups, the most common living arrangement was the elder living in the same household as the caregiver, although Black/African-American caregivers were more likely to live apart from the elder. This pattern likely reflects the fact that adult children were most common as caregivers among the Black/African-American sample (63%). Adult children also comprised 55% of the Hispanic/Latino group and 46% of the White caregivers. Spouses comprised only 18% of the caregivers in the Black/African-American sample and 34% of the caregivers in the Hispanic/Latino group. Other less immediate family members were more prevalent among Black/African-American caregivers (16%) than among White caregivers (5%) or Hispanic/Latino caregivers (11%).

**TABLE 1.7. CAREGIVER DEMOGRAPHIC CHARACTERISTICS BY RACE (N=377)**

	All Groups		White		Black/African-American		Hispanic/Latino	
	377	100%	168	44.6%	116	30.8%	93	24.7%
	N	%	N	%	N	%	N	%
*Relationship to elder								
Spouse	131	34.7%	78	46.4%	21	18.1%	32	34.4%
Adult child / child-in-law	201	53.3%	77	45.8%	73	62.9%	51	54.8%
Other relative	38	10.1%	9	5.4%	19	16.4%	10	10.8%
Friend	7	1.9%	4	2.4%	3	2.6%	0	0.0%
Professional care manager	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Self	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Gender								
Male	106	28.1%	54	32.1%	24	20.7%	28	30.1%
Female	271	71.9%	114	67.9%	92	79.3%	65	69.9%
Age (in years)								
44 or less	46	12.2%	11	6.5%	19	16.4%	16	17.2%
45 - 54	60	15.9%	29	17.3%	19	16.4%	12	12.9%
55 - 64	73	19.4%	33	19.6%	19	16.4%	21	22.6%
65 - 74	77	20.4%	33	19.6%	32	27.6%	12	12.9%
75 - 84	57	15.1%	31	18.5%	9	7.8%	17	18.3%
Over 84	8	2.1%	7	4.2%	0	0.0%	1	1.1%
Unknown	56	14.9%	24	14.3%	18	15.5%	14	15.1%
*Mean age	60.9		63.5		58.2		59.7	
*Marital Status								
Single/Divorced	80	21.2%	20	11.9%	39	33.6%	18	19.4%
Married	260	69.0%	139	82.7%	59	50.9%	66	71.0%
Widowed	28	7.4%	6	3.6%	15	12.9%	6	6.5%
Unknown	9	2.4%	3	1.8%	3	2.6%	3	3.2%
*Education								
Less than high school	79	21.0%	23	13.7%	24	20.7%	31	33.3%
Completed high school	94	24.9%	42	25.0%	36	31.0%	16	17.2%
Vocational training	19	5.0%	10	6.0%	4	3.4%	6	6.5%
Attended college	72	19.1%	44	26.2%	20	17.2%	7	7.5%
College graduate	58	15.4%	29	17.3%	21	18.1%	10	10.8%
Graduate work	18	4.8%	11	6.5%	2	1.7%	4	4.3%
Unknown	37	9.8%	9	5.4%	9	7.8%	19	20.4%
*Employment								
Full-time	91	24.1%	38	22.6%	28	24.1%	25	26.9%
Part-time	71	18.8%	35	20.8%	17	14.7%	19	20.4%
Unemployed	39	10.3%	13	7.7%	16	13.8%	10	10.8%
Retired	142	37.7%	72	42.9%	46	39.7%	24	25.8%
Other/unknown	17	4.5%	7	5.4%	7	9.8%	3	15.1%
Unknown	17	4.5%	3	1.8%	2	1.7%	12	12.9%

\* Significant differences between ethnic groups at p <= .05

**TABLE 1.7. CAREGIVER DEMOGRAPHIC CHARACTERISTICS BY RACE (N=377)--Continued**

	All Groups		White		Black/African-American		Hispanic/Latino	
	377	100%	168	44.6%	116	30.8%	93	24.7%
	N	%	N	%	N	%	N	%
<b>*Income</b>								
Not Reported	81	21.5%	29	17.3%	21	18.1%	31	33.3%
Reported	296	78.5%	139	82.7%	95	81.9%	62	66.7%
Under \$5,000	44	14.9%	9	6.5%	16	16.8%	16	25.8%
\$5,000-\$15,000	121	40.9%	48	34.5%	40	42.1%	35	56.5%
\$15,001-\$30,000	76	25.7%	47	33.8%	21	22.1%	6	9.7%
\$30,001-\$50,000	37	12.5%	23	16.5%	12	12.6%	3	4.8%
Over \$50,000	18	6.1%	12	8.6%	6	6.3%	2	3.2%
<b>Number of Persons in Household</b>								
1 person	45	11.9%	18	10.7%	9	7.8%	18	19.4%
2 persons	151	40.1%	87	51.8%	33	28.4%	31	33.3%
3 or 4 persons	116	30.8%	44	26.2%	46	39.7%	26	28.0%
5 or more persons	57	15.1%	15	8.9%	24	20.7%	18	19.4%
Unknown	8	2.1%	4	2.4%	4	3.4%	0	0.0%
<b>*Help Provided by Elder (Mean)</b>	1.5		1.8		1.4		1.6	
<b>Length of caregiving before program entry (in months)</b>								
0 - 6	52	13.8%	22	13.1%	19	16.4%	11	11.8%
7 - 12	36	9.5%	19	11.3%	8	6.9%	9	9.7%
13 - 24	63	16.7%	25	14.9%	29	25.0%	9	9.7%
25 - 36	52	13.8%	23	13.7%	22	19.0%	7	7.5%
37 - 72	70	18.6%	36	21.4%	11	9.5%	23	24.7%
72 or more	60	15.9%	27	16.1%	17	14.7%	16	17.2%
Unknown	44	11.7%	16	9.5%	10	8.6%	18	19.4%
Mean length of caregiving	42.0		42.7		38.9		44.7	
<b>*Back-Up Caregiver Available</b>								
No	186	49.3%	92	54.8%	43	37.1%	51	54.8%
Yes	149	39.5%	51	30.4%	57	49.1%	41	44.1%
Unknown	42	11.1%	25	14.9%	16	13.8%	1	1.1%
<b>*Driving Distance from Elder (mins.)</b>								
Lives in same household	306	81.2%	148	88.1%	91	78.4%	71	76.3%
1 - 10	25	6.6%	7	4.2%	10	8.6%	6	6.5%
11 - 30	18	4.8%	3	1.8%	12	10.3%	2	2.2%
Over 30	2	0.5%	2	1.2%	0	0.0%	0	0.0%
Other/Unknown	26	6.9%	8	4.8%	3	2.6%	14	15.1%

\* Significant differences between ethnic groups at p <= .05

There tended to be greater sharing of caregiving responsibilities among Black/African-American caregivers. More Black/African-American caregivers (49%) received help with caregiving tasks from other persons than did White (30%) or Hispanic/Latino caregivers (44%) and a higher proportion of these caregivers knew someone who could provide care in their absence. The greater availability of back-up caregivers may reflect the greater tendency for Black/African-American caregivers to live in households with three or more persons. It is also of interest to note that Black/African-American caregivers were more likely than any other group to receive assistance from the care recipient. (Assistance provided by the elder was measured by five dichotomous items that are described in Appendix 1C).

Characteristics related to caregivers' health and well-being are shown in Table 1.8. Although level of physical health was similar across groups, emotional health varied by ethnicity. Hispanic/Latino caregivers expressed more satisfaction with their lives than did Blacks/African-Americans or Whites. Black/African-American caregivers exhibited fewer symptoms of depression, as measured by the CESD depression scale (see Appendix 1C; reliability of .80), than did members of other groups.

**TABLE 1.8. CAREGIVERS' HEALTH AND WELL-BEING (N=377)**

	<b>White</b>		<b>Black/Afr-American</b>		<b>Hisp/Latino</b>		<b>All Groups</b>	
	168	44.6%	116	30.8%	93	24.7%	377	100.0%
	Mean		Mean		Mean		Mean	
<b>*Life Satisfaction</b>	2.1		2.2		2.4		2.2	
<b>*Depression</b>	12.3		10.9		12.5		11.9	
<b>Physical Health</b>	5.7		5.6		6.0		5.7	
<b>Detriment to Work while Caregiving</b>	1.3		0.8		1.2		1.1	

\* Significant differences between ethnic groups at  $p \leq .05$

### ***Acculturation of Hispanic/Latino Caregivers***

When families enrolled in the ADDGS program, they were asked about their language preferences and their country of origin. A preference for a language other than English was

only prevalent among the Hispanic/Latino families. As shown in Table 1.9, more than three-quarters of both the caregivers and elders from these families expressed a preference for using Spanish. Both groups preferred to speak Spanish, and were more proficient in Spanish than English, although caregivers were more proficient in English than were elders.

Hispanics/Latinos who cared for a parent rated their English abilities higher than did spouse caregivers. The majority of both elders (70%) and caregivers (51%) were monolingual. A larger segment of Hispanic/Latino caregivers (48%) than elders (30%) were bilingual in Spanish and English. Only one caregiver claimed fluency in three or more languages.

In regard to country of origin, the highest proportion of Hispanic/Latino elders and caregivers originated in Mexico, followed closely by Cuba. The Hispanic/Latino caregivers represented in the sample did not have a high level of acculturation into White American society, as measured by a composite of four items that asked about their ethnic preferences for friends, social

**TABLE 1.9. HISPANIC/LATINO ACCULTURATION AND HERITAGE**

	Hispanic/Latino Elder		Hispanic/Latino Caregiver	
	93	100.0%	93	100.0%
	N	%	N	%
<b>Language of Preference</b>				
English	19	20.4%	22	23.7%
Spanish	74	79.6%	71	76.3%
Other/Unknown	0	0.0%	0	0.0%
<b>Number of Languages Spoken</b>				
One	65	69.9%	47	50.5%
Two	28	30.1%	45	48.4%
Three or more	0	0.0%	1	1.1%
<b>Country of Origin</b>				
United States	22	23.7%	22	23.7%
Mexico	29	31.2%	29	31.2%
Cuba	25	26.9%	26	28.0%
Central America (not MX)	4	4.3%	5	5.4%
South America	10	10.8%	10	10.8%
Other/Unknown	3	3.2%	1	1.1%
		<b>Mean Stnd. Dev.</b>		
<b>Language Proficiency</b>			<b>Mean Stnd. Dev.</b>	
English (6 - 24)	10.80	6.37	15.05	6.61
Spanish (6 - 24)	19.39	5.83	22.68	3.46
<b>Social Acculturation</b>				
(4 - 16)			7.33	3.10

gatherings, and visitors, based upon five-point response sets. The composite measure had a reliability of .84, and is described in more detail in Appendix 1C.

The sample of families included in the client satisfaction interview was very comparable in demographic characteristics to the sample of families included in the longitudinal analyses of respite use in Study Two (see Tables 2.9 and 2.10). The distributions of gender, marital status, age, and service use prior to the demonstration are nearly identical between the two samples. The two samples were somewhat different in income levels and geographic location. The average incomes of elders in the interview sample were more densely concentrated at lower levels than was the case in the longitudinal sample. Also, a larger segment of the interview sample than of the longitudinal sample resided in urban areas. A smaller percentage of elders in the interview sample lived alone, and more lived with adult children and in larger households. These differences are likely due to the increased prevalence of adult children as caregivers in the interview sample.

Elders' functional status was also similar, but with a few minor differences. The interview and longitudinal samples were very similar in respect to Alzheimer's diagnostic status and ADL levels. Members of the interview sample required slightly less assistance with IADL tasks, but exhibited more frequent problematic behavior.

Demographic characteristics of the caregivers included in the two study samples were also similar. Caregivers did not differ with respect to gender, age, marital status, income, length of caregiving before the demonstration, and driving distance from the elder. Adult children did, however, comprise a larger proportion of the interview sample (53%) than in the longitudinal sample (46%) in Study Two. As a group, caregivers who participated in the interview also had slightly higher average levels of educational attainment. Finally, a smaller segment of caregivers in the interview sample worked full-time, and more were retired, than were those in the longitudinal sample.

### **Data Analysis**

To assess the cultural differences in beliefs and views of respite services initially, a series of bivariate analyses was conducted for each aspect of culture (i.e. ethnicity, geography, and relationship). Specifically, a one-way analysis of variance was performed to contrast cultural

groups on each outcome measure of interest. If the F-test was significant, a post-hoc test was then conducted to ascertain the nature of the differences between groups. Although many types of post-hoc tests are available, they differ primarily in how they adjust the observed significance level. In the absence of *a priori* hypotheses, the post-hoc tests in this study were straightforward; multiple comparisons of means, or what Cohen and Cohen (1975) refer to as “protected t-tests”. They are protected in the sense that they are only performed after the null hypothesis of “no difference among means” has been rejected at the .05 level.

As previously discussed, various elements within the study sample that comprise the notion of culture in the present study (i.e., ethnicity, urban/rural location, and relationship of the caregiver to the elder) are inter-related. For example, Hispanics/Latinos in the present sample tended to reside in urban areas. Black/African-American caregivers were proportionately more likely to be children or “others” (i.e., non-spouse, non-child caregivers) compared with White caregivers. Therefore, in addition to examining the simple bivariate relationship between some aspect of culture (e.g., ethnicity) and some outcome of interest (e.g., client satisfaction with services), it is instructive to examine these same relationships controlling for the influence of the other aspects of culture (i.e., urban/rural location and relationships).

In the tables and figures that follow, the effect of each specific element of culture on each of the outcomes of interest is reported in three ways. First, the mean scores for each dependent variable are reported for each group in Tables 1.10 and 1.12. Asterisks denote mean scores that differ significantly by group. Second, incremental F statistics are reported for each outcome variable in Tables 1.11 and 1.13. The incremental F statistics correspond to the increment in explained variance that can be attributed to the specific element of culture (i.e. ethnicity, geography, or relationship) that is under consideration. The incremental F statistic is used to test for significance of the *incremental increase in explained variance of the dependent variable* that can be attributed to an element of culture when it is added to a model that already includes the other two elements of culture. For example, the incremental F-test would address the question: “What is the effect of ethnicity on satisfaction, net of the effects of urban/rural location and relationship to the elder, on satisfaction?” Finally, if the incremental F statistic was significant, a post-hoc test was then conducted to ascertain the nature of differences among groups. Findings from the post-hoc analyses are detailed in Figures 1.2 through 1.19.

## FINDINGS

### Caregivers' Beliefs and Attitudes

Findings from the bivariate analyses shown in shown Table 1.10 revealed that many differences in beliefs and attitudes were associated with ethnicity. In fact, differences between ethnic groups were found to be statistically significant for every outcome measure except caregivers' reports of family conflict. Only two differences in mean scores for beliefs and attitudes were found to be related to geographic location. Specifically, caregivers in urban areas reported higher levels of obligation and a higher adherence to traditional family values. Attitudes and beliefs concerning family relationships varied by caregivers' relationship to elder. Spouses reported both more affection for the elder and greater obligation to provide care. They also reported lower adherence to family values and less family conflict. Finally, caregivers other than spouses and children reported more agreement with the notion that the government should assist with elder care.

**TABLE 1.10. DIFFERENCES IN MEANS BY CULTURE IN CAREGIVERS' BELIEFS AND ATTITUDES**

	All Groups	Ethnicity			Geography		Relationship		
	N=377	White N=168	Black N=116	Hispanic N=93	Rural N=153	Urban N=191	Child N=200	Spouse N=131	Other N=46
	Mean	Mean	Mean	Mean	Mean	Mean	Mean	Mean	Mean
<b>FAMILY RELATIONSHIPS</b>									
Affection for Elder	27.8	27.3**	28.5	27.9	27.5	28.1	27.3**	28.5**	27.9
Obligation to Care	27.9	27.6	28.3	27.9	27.5*	28.3*	27.5	28.7**	27.1
Family Values	28.8	27.0**	29.3	31.5	28.0**	29.7**	29.1	27.8**	30.6
Respect for Elders	4.7	3.9	4.3	6.4**	3.9	5.2	4.5	4.8	4.8
Family Conflict	1.5	1.5	1.6	1.5	1.5	1.5	1.7	1.2**	1.8
Social Contact	0.5	0.6	0.6	0.4*	0.6	0.5	0.5	0.6	0.5
<b>ATTITUDES ABOUT HELP</b>									
Guilt at Respite Use	14.3	14.6	14.4	13.8*	14.4	14.3	14.3	14.4	14.2
Government Asst.	8.5	8.2*	8.8	8.7	8.4	8.7	8.6	8.2*	9.0
Satisfaction with Help	7.3	7.1	7.0	7.9**	7.1	7.5	7.2	7.6	6.9
<b>ATTITUDES ABOUT RELIGION</b>									
Religiosity	10.3	9.9**	10.7**	10.4	10.1	10.4	10.4	10.1	10.3
Strength of Beliefs	6.7	6.3	7.2*	6.6	6.6	6.8	6.8	6.5	6.6
Support from Congreg.	7.0	6.6	8.0**	6.2	7.2	6.9	6.9	6.8	7.5

\* Group difference significant at  $p \leq .05$  prior to controlling for covariates

\*\* Groups difference significant at  $p \leq .01$  prior to controlling for covariates

As indicated by the F-statistics shown in Table 1.11, the majority of the bivariate differences associated with each aspect of culture remained statistically significant when the effects of the other two aspects of culture were controlled. Only two differences did not retain statistical significance. The differences between urban and rural caregivers in their reported obligation to care did not persist when covariates representing ethnicity and relationship were added to the test model. Similarly, the difference between spouses and children in their expectations for governmental assistance with care did not remain when covariates representing ethnicity and geography were included in the test model.

As detailed in Figures 1.2 and 1.3, *affection for elder* varied by ethnicity and relationship. A higher proportion of Black/African-American (Figure 1.2) and spouse caregivers (Figure 1.3) expressed high levels of affection. Spouse caregivers also expressed more feelings of *obligation to care* than did caregivers of other relationships (Figure 1.4).

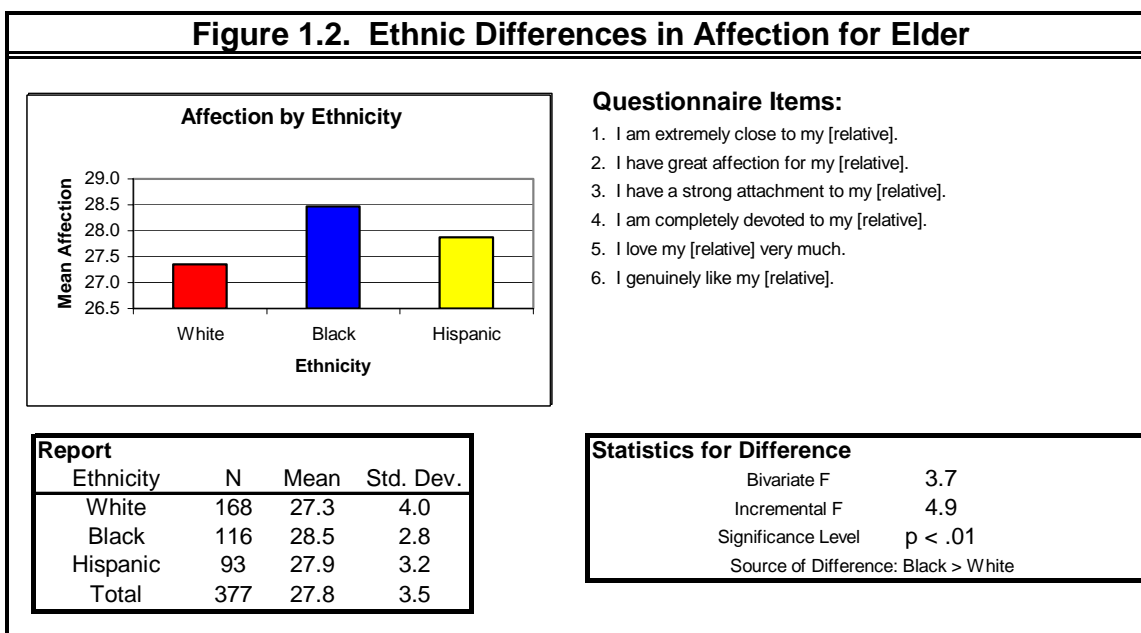
Differences among caregivers in expressed family values were associated with both ethnicity and geographic residence. As shown in Figure 1.5, Hispanics/Latinos had the highest scores on this measure, reflecting the highest adherence to traditional views. White caregivers expressed views that were the least traditional, with Blacks/African-Americans' views in the middle. Interestingly, the views of spouse caregivers differed significantly from adult child caregivers and other, more distant relatives. Spouses were least likely to express traditional views (Figure 1.6).

Differences in caregivers' levels of respect for elders were also associated with both ethnicity and geographic residence. Hispanics/Latinos reported significantly higher levels of respect for elders than did either of the other two groups (Figure 1.7). Similarly, persons residing in urban areas had higher scores on the measure of respect for elders than did caregivers residing in rural areas. *Respect for elders* differed between both ethnic and geographic groups (Figures 1.7 and 1.8). The amount of *family conflict* caregivers perceived about caregiving issues varied based upon relationship. Fewer spouse caregivers reported familial conflict than did adult children or other relatives (Figure 1.9).

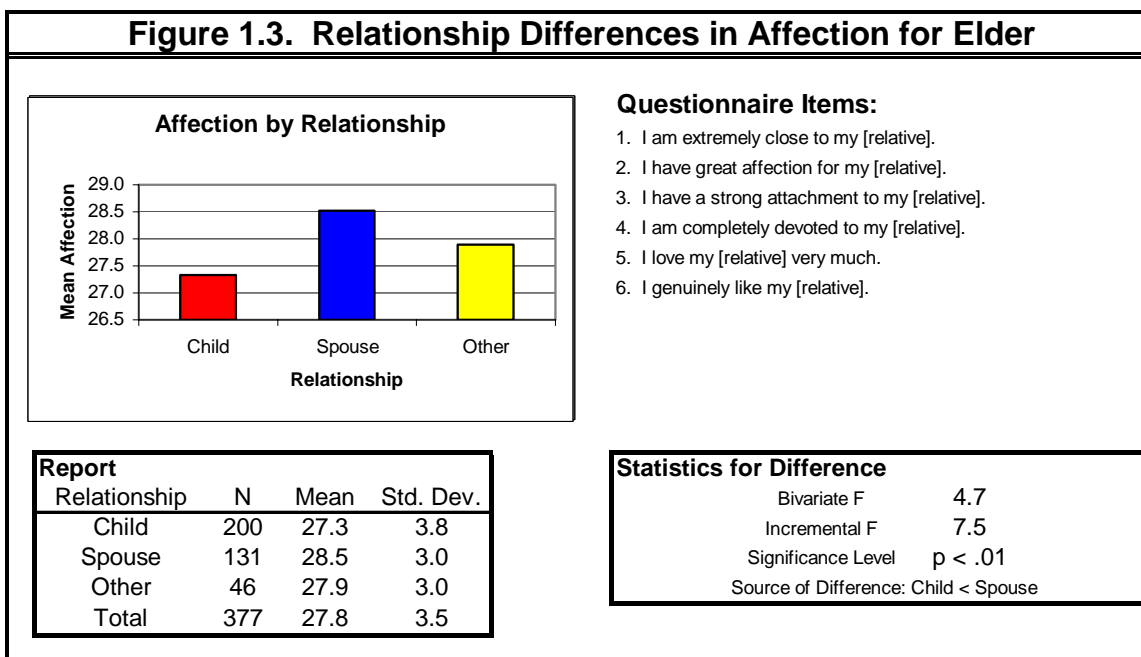
**TABLE 1.11. TESTS FOR DIFFERENCES IN CAREGIVERS' BELIEFS AND ATTITUDES BY MEASURES OF CULTURE**

	Incremental F Statistics		
	<u>Ethnicity<sup>A</sup></u>	<u>Geography<sup>B</sup></u>	<u>Relationship<sup>C</sup></u>
<b>FAMILY RELATIONSHIPS</b>			
Affection for Elder	4.9*	0.0	7.5*
Obligation to Care	2.4	2.6	9.7*
Family Values	17.3*	0.0	3.6*
Respect for Elders	30.8*	3.9*	1.8
Family Conflict	0.6	0.2	11.1*
Social Contact	3.2*	0.0	1.2
<b>ATTITUDES REGARDING HELP</b>			
Guilt at Respite Use	6.7*	1.7	0.1
Government Asst.	3.6*	0.0	2.0
Satisfaction with Help	7.1*	0.0	1.6
<b>ATTITUDES REGARDING RELIGION</b>			
Religiosity	4.2*	0.2	0.0
Strength of Beliefs	7.0*	0.0	0.6
Support from Congreg.	8.1*	1.8	0.9
* Significant differences between ethnic groups at $p \leq .05$			
<sup>A</sup> Covariates included in model: Relationship, Geographic Location			
<sup>B</sup> Covariates included in model: Ethnicity, Relationship			
<sup>C</sup> Covariates included in model: Ethnicity, Geographic Location			

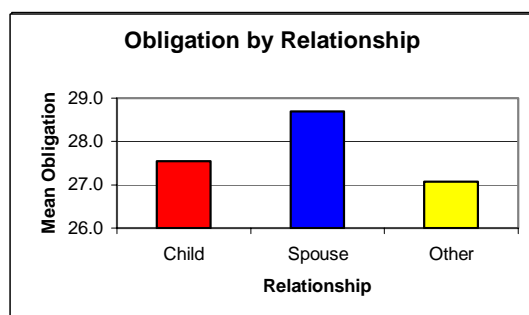
**Figure 1.2. Ethnic Differences in Affection for Elder**



**Figure 1.3. Relationship Differences in Affection for Elder**



**Figure 1.4. Relationship Differences in Obligation to Care**



**Questionnaire Items:**

1. It is my duty to care for my [relative].
2. I personally must protect my [relative]'s interests.
3. I feel I have to assume caregiving tasks for my [relative].
4. I am morally bound to care for my [relative].
5. It is my obligation to help my [relative].
6. I am responsible for my [relative].

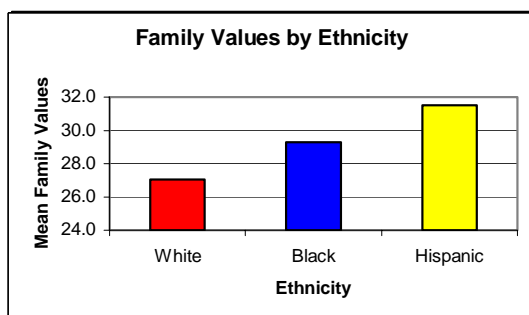
**Report**

Relationship	N	Mean	Std. Dev.
Child	200	27.5	3.3
Spouse	131	28.7	2.3
Other	46	27.1	4.1
Total	377	27.9	3.2

**Statistics for Difference**

Bivariate F	7.2
Incremental F	9.7
Significance Level	p < .01
Source of Difference: Spouse > Child and Other	

**Figure 1.5. Ethnic Differences in Family Values**



**Questionnaire Items:**

1. When someone has problems, s/he can count on help from his/her relatives.
2. People should seek the advice of older relatives in important matters.
3. A person should share his/her home with uncles, aunts, or first cousins if they are in need.
4. It is still important to obey the wishes of parents/older relatives.
5. True wisdom comes with age.
6. If a relative told you he is in financial difficulty, you would help as much as you could.
7. One can count on help from relatives to solve most problems.
8. Aging parents should live with their relatives.

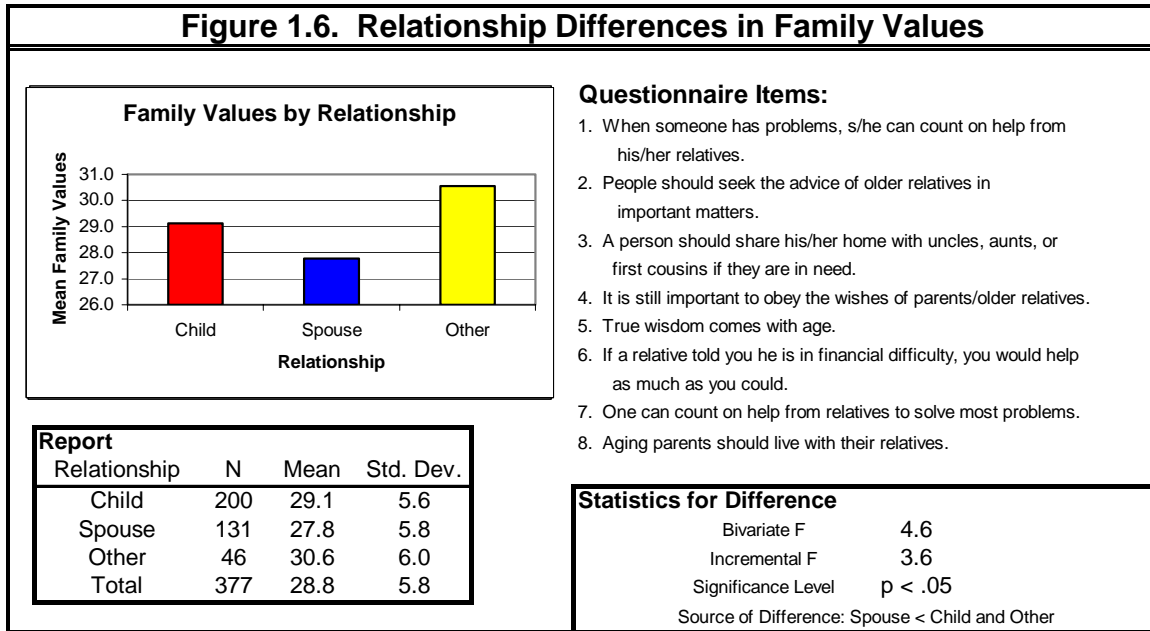
**Report**

Ethnicity	N	Mean	Std. Dev.
White	168	27.0	5.5
Black	116	29.3	5.6
Hispanic	93	31.5	5.2
Total	377	28.8	5.8

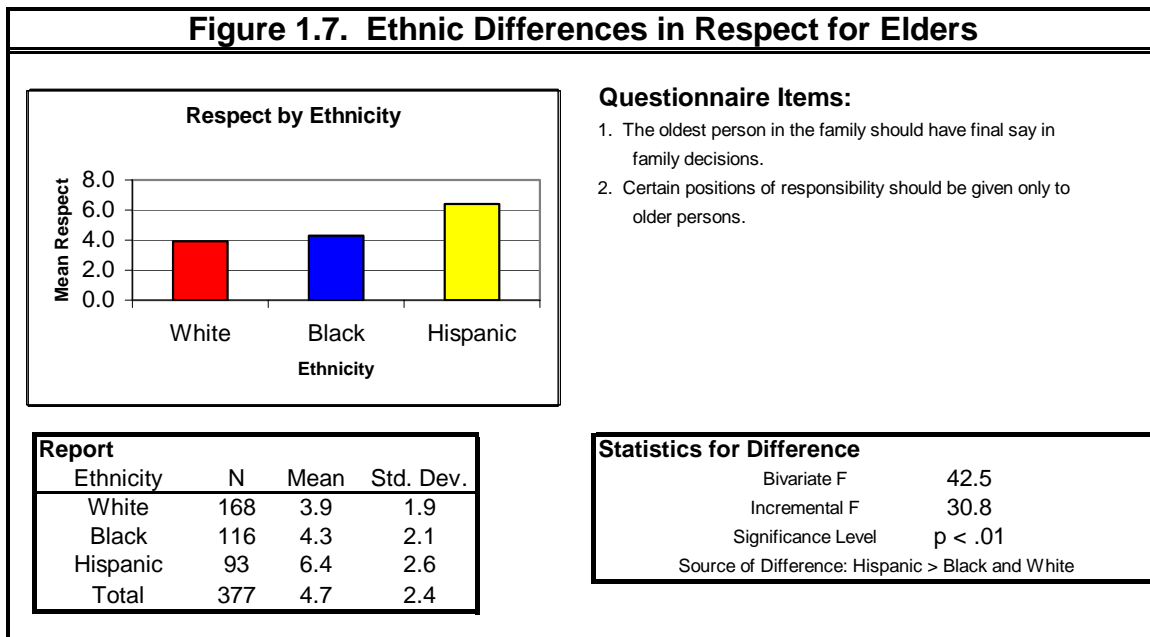
**Statistics for Difference**

Bivariate F	20.4
Incremental F	17.3
Significance Level	p < .01
Source of Difference: Hispanic > Black; Black > White	

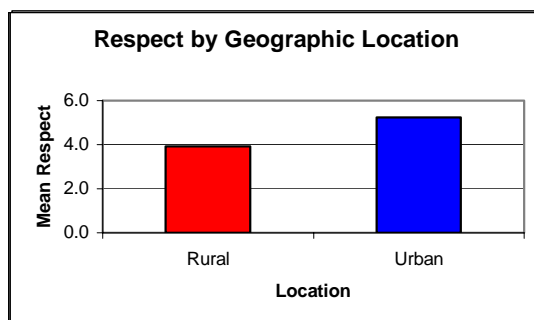
**Figure 1.6. Relationship Differences in Family Values**



**Figure 1.7. Ethnic Differences in Respect for Elders**



**Figure 1.8. Geographic Differences in Respect for Elders**



**Questionnaire Items:**

1. The oldest person in the family should have final say in family decisions.
2. Certain positions of responsibility should be given only to older persons.

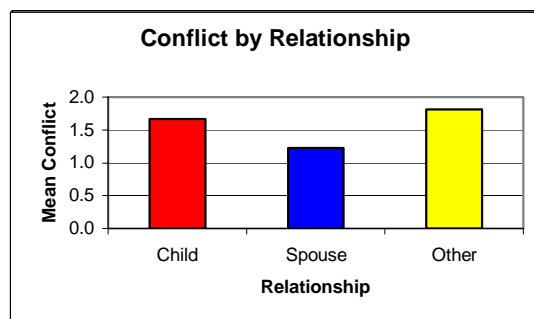
**Report**

Location	N	Mean	Std. Dev.
Rural	153	3.9	2.0
Urban	191	5.2	2.5
Total	344	4.7	2.4

**Statistics for Difference**

Bivariate F	27.5
Incremental F	3.9
Significance Level	$p < .05$
Source of Difference:	Urban > Rural

**Figure 1.9. Relationship Differences in Family Conflict**



**Questionnaire Items:**

1. To what extent has there been any family conflict over caregiving for your [relative]?
  - 1 = no conflict
  - 2 = a little conflict
  - 3 = some conflict
  - 4 = a lot of conflict

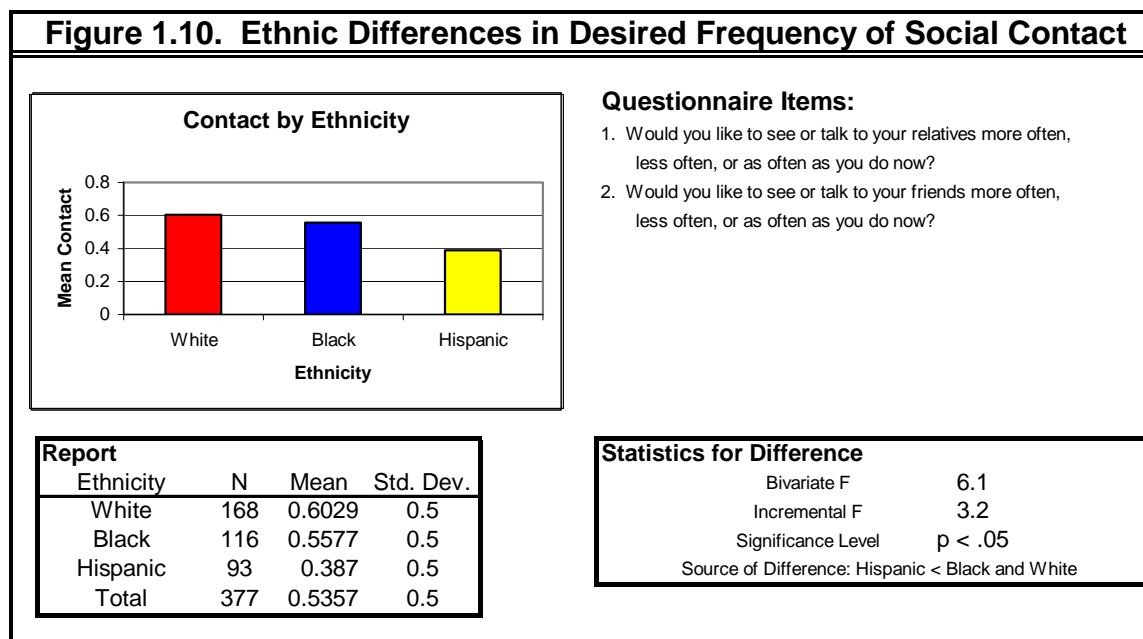
**Report**

Relationship	N	Mean	Std. Dev.
Child	200	1.7	1.0
Spouse	131	1.2	0.6
Other	46	1.8	1.1
Total	377	1.5	0.9

**Statistics for Difference**

Bivariate F	12.6
Incremental F	11.1
Significance Level	$p < .01$
Source of Difference:	Spouse < Child and Other

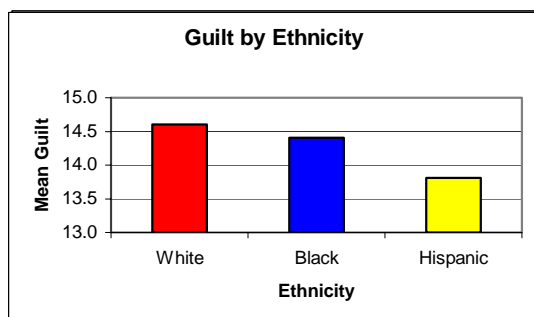
The desire for more frequent social contact differed only by ethnicity. Hispanic/Latino caregivers were most content, and Whites and Black/African-Americans less so, with their current patterns of contact. This finding is illustrated in Figure 1.10.



Groups also held differing attitudes about help with caregiving. A smaller proportion of Hispanic/Latino caregivers than caregivers from other ethnic groups felt *guilty* about using respite services, as shown in Figure 1.11. Similarly, White caregivers expressed more resistance to accepting *government assistance* than did other groups (Figure 1.12). *Satisfaction with help with caregiving* varied by ethnicity as well, with Hispanics/Latinos expressing more satisfaction with the informal help that they received than did caregivers from other ethnic groups. This finding is depicted in Figure 1.13.

Ethnic distinctions were correlated with religious differences. On average, White caregivers expressed less *religiosity* than other groups, as seen in Figure 1.14. Variation in strength of religious beliefs mirrored the patterns of religiosity. Black/African-American caregivers' beliefs were strongest, as shown in Figure 1.15. Finally, ethnic groups differed in the amount of support they received from their congregation. A larger proportion of Black/African-American caregivers than other groups felt that they received support, as Figure 1.16 illustrates.

**Figure 1.11. Ethnic Differences in Guilt at Respite Use**



**Questionnaire Items:**

1. My family thinks less of me if I use respite for my [relative]'s care.
2. My family doesn't think we should use respite services for our [relative].
3. People outside my family would think less of me if they knew that I used respite services.

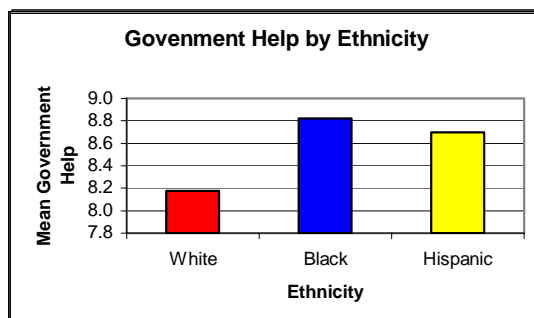
**Report**

Ethnicity	N	Mean	Std. Dev.
White	168	14.6	1.4
Black	116	14.4	1.6
Hispanic	93	13.8	2.4
Total	377	14.3	1.8

**Statistics for Difference**

Bivariate F	6.4
Incremental F	6.7
Significance Level	p < .01
Source of Difference: Hispanic < Black and White	

**Figure 1.12. Ethnic Differences in Attitudes toward Government Assistance**



**Questionnaire Items:**

1. The government should provide more money for respite services.
2. The government should help families care for persons at home.

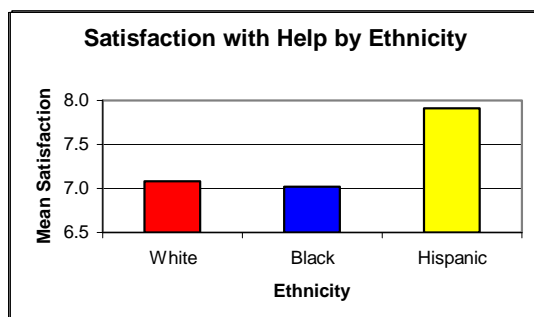
**Report**

Ethnicity	N	Mean	Std. Dev.
White	168	8.2	2.1
Black	116	8.8	1.6
Hispanic	93	8.7	1.9
Total	377	8.5	1.9

**Statistics for Difference**

Bivariate F	4.6
Incremental F	3.6
Significance Level	p < .05
Source of Difference: White < Hispanic and Black	

**Figure 1.13. Ethnic Differences in Satisfaction with Help with Caregiving**



**Questionnaire Items:**

1. How satisfied are you with the amount of help you have received from others in assisting your [relative]?
2. How satisfied are you with the amount of emotional support you have received from others in the last 6 months?

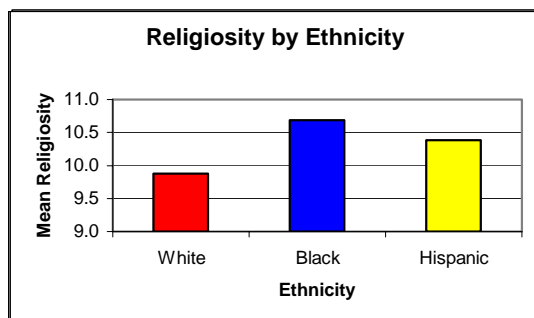
**Report**

Ethnicity	N	Mean	Std. Dev.
White	168	7.1	2.0
Black	116	7.0	2.0
Hispanic	93	7.9	2.1
Total	377	7.3	2.0

**Statistics for Difference**

Bivariate F	6.4
Incremental F	7.1
Significance Level	p < .01
Source of Difference: Hispanic > White and Black	

**Figure 1.14. Ethnic Differences in Religiosity**



**Questionnaire Items:**

1. Religion is a source of great strength and comfort to you.
2. You try hard to carry your religious beliefs over into all your other dealings in life.
3. You consider yourself to be a very spiritual person.

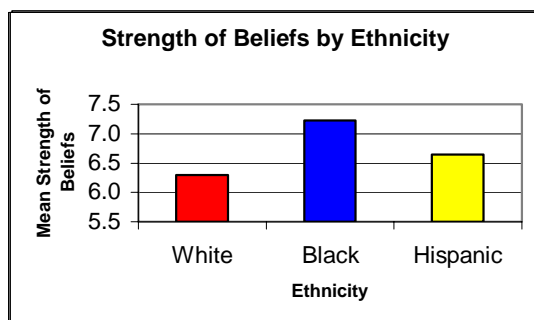
**Report**

Ethnicity	N	Mean	Std. Dev.
White	168	9.9	2.1
Black	116	10.7	1.7
Hispanic	93	10.4	1.7
Total	377	10.3	1.9

**Statistics for Difference**

Bivariate F	6.5
Incremental F	4.2
Significance Level	p < .01
Source of Difference: White < Black and Hispanic	

**Figure 1.15. Ethnic Differences in Strength of Beliefs**



**Questionnaire Items:**

1. You look to God for strength, support, and guidance in crises.
2. You try to find the lesson from God in crises.

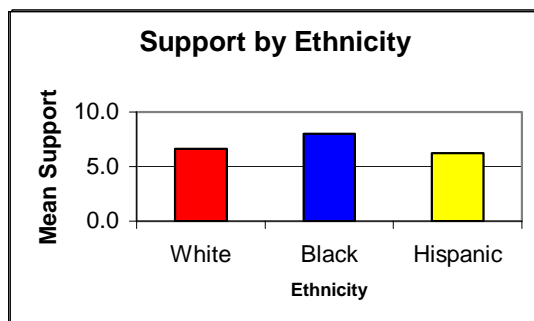
**Report**

Ethnicity	N	Mean	Std. Dev.
White	168	6.3	1.9
Black	116	7.2	1.5
Hispanic	93	6.6	2.0
Total	377	6.7	1.8

**Statistics for Difference**

Bivariate F	9.2
Incremental F	7.0
Significance Level	$p < .01$
Source of Difference: Black > Hispanic and White	

**Figure 1.16. Ethnic Differences in Support from Religious Congregation**



**Questionnaire Items:**

1. How often do people in your congregation listen to you talk about your private problems and concerns?
2. How often do the people in your congregation express interest and concern in your well-being?
3. If you had a problem or were faced with a difficult situation, how much comfort would the people in your congregation be willing to give you?

**Report**

Ethnicity	N	Mean	Std. Dev.
White	168	6.6	3.1
Black	116	8.0	2.4
Hispanic	93	6.2	3.0
Total	377	7.0	3.0

**Statistics for Difference**

Bivariate F	11.8
Incremental F	8.1
Significance Level	$p < .01$
Source of Difference: Black > White or Hispanic	

### Clients' Views of Services

Groups were equally satisfied with respite services, without regard to culture. Although the mean scores reflecting caregiver's assessment of communication difficulties and institutional barriers reported in Table 1.12 were different at the zero-order level, the strength of this relationship generally diminished substantially when covariates representing ethnicity, relationship, and type of services were included in analyses. No differences associated with the caregivers' relationship to the elder were observed for any of the outcome measures. Ethnicity and service type (ADC versus In-home) differences were initially observed on only three measures (Table 1.12). As shown in Table 1.13, however, these differences remained significant only for the communication difficulties and staff friendliness after controls for other cultural characteristics and magnitude of need (ADL/IADL and problem behavior) were included in the analyses.

**TABLE 1.12. DIFFERENCES IN MEANS BY CULTURE FOR CLIENT SATISFACTION AND VIEWS OF SERVICES**

	All Groups	Ethnicity			Geography		Relationship			Service Type		
		White	Black	Hispanic	Rural	Urban	Child	Spouse	Other	DC	INH	Both
	N=377 Mean	N=168 Mean	N=116 Mean	N=93 Mean	N=153 Mean	N=191 Mean	N=200 Mean	N=131 Mean	N=46 Mean	N=143 Mean	N=139 Mean	N=52 Mean
Client Satisfaction	13.9	13.9	14.2	13.5	14.0	14.0	13.8	14.0	14.1	14.1	14.0	13.4
Communication Difficulties	6.8	6.2	6.1	8.9**	6.2**	7.3**	6.8	7.1	6.3	6.1	6.4	7.4*
Clear Expectations	13.3	13.2	13.4	13.2	13.1	13.5	13.2	13.4	13.5	13.2	13.4	12.6
Access to Services	10.8	10.1*	11.1	11.7	10.5	11.1	10.6	11.0	11.3	11.2*	10.2	9.7
Staff Friendliness	19.2	19.4	19.3	18.8**	19.3	19.2	19.2	19.1	19.6	19.4	19.2	19.0
Shared Values	13.7	13.7	13.8	13.6	13.7	13.8	13.6	13.7	14.0	13.8	13.8	13.0
Institutional Barriers	10.9	10.6	10.7	11.8*	10.4**	11.5**	11.1	10.9	10.2	10.7	10.6	11.5
Trust in Staff <sup>1</sup>	18.6	18.8	18.9	18.0*	19.0	18.6	18.6	18.6	18.9	~	18.9	17.8
Appropriate Activities <sup>2</sup>	13.0	13.1	13.4	12.5	13.1	13.1	12.9	12.7	13.7	13.3	~	12.0

\* Group difference significant at  $p \leq .05$  prior to controlling for covariates

\*\* Group difference significant at  $p \leq .01$  prior to controlling for covariates

<sup>1</sup> This question was only asked of those that used in-home respite.

<sup>2</sup> This question was only asked of those that used day care / group respite.

A larger proportion of Hispanic/Latino caregivers reported greater difficulty with communication relative to other groups (Figure 1.17). Also, caregivers who utilized both day care and in-home respite services expressed more difficulty with communication than did users of only one service (Figure 1.18). Perceptions of *access to services* also varied by ethnicity. Accessibility was rated lowest by White caregivers (Figure 1.19).

**TABLE 1.13. TESTS FOR DIFFERENCES IN CLIENTS' VIEWS OF SERVICES BY MEASURES OF CULTURE**

	Incremental F Statistics			
	<u>Ethnicity<sup>A</sup></u>	<u>Geography<sup>B</sup></u>	<u>Relationship<sup>C</sup></u>	<u>Service Type<sup>D</sup></u>
<b>Client Satisfaction</b>	0.2	0	0.3	0.2
<b>Communication Diffs</b>	10.8*	0.6	1.6	12.4*
<b>Clear Expectations</b>	0.1	1.9	1.6	0.7
<b>Access to Services</b>	5.7*	0.2	1.0	1.8
<b>Staff Friendliness</b>	1.4	0.3	2.1	0.4
<b>Shared Values</b>	0.2	0.3	1.2	0.9
<b>Redtape</b>	0.5	2.5	0.7	0.1
<b>Trust in Staff<sup>1</sup></b>	0.2	1.7	0.3	0.6
<b>Approp. Activities<sup>2</sup></b>	0.1	0.2	2.1	0.3

\* Significant differences between ethnic groups at  $p \leq .05$

<sup>1</sup> This question was only asked of those that used in-home respite.

<sup>2</sup> This question was only asked of those that used adult day care / group respite.

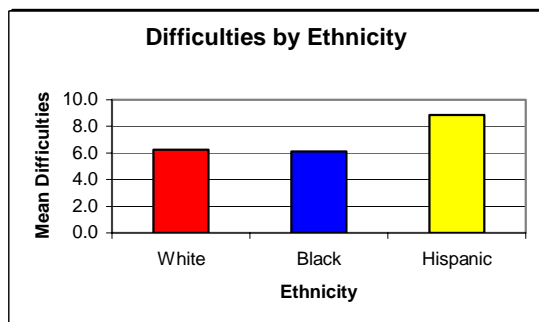
<sup>A</sup> Covariates included in model: Relationship, Geographic Location, IADL, ADL, Problem Behavior, Respite Type

<sup>B</sup> Covariates included in model: Ethnicity, Relationship, ADL, IADL, Problem Behavior, Respite Type

<sup>C</sup> Covariates included in model: Ethnicity, Geographic Location, IADL, ADL, Problem Behavior, Respite Type

<sup>D</sup> Covariates included in model: Ethnicity, Geographic Location, Relationship, IADL, ADL, Problem Behavior

**Figure 1.17. Ethnic Differences in Communication Difficulties**



**Questionnaire Items:**

1. When the respite workers discuss my [relative]'s health and care needs with me, they use words I understand.
2. How easy is it for you to talk with the respite workers?
3. When talking with the respite worker, how difficult is it to explain what help you want?
4. Workers at the respite program speak your language.

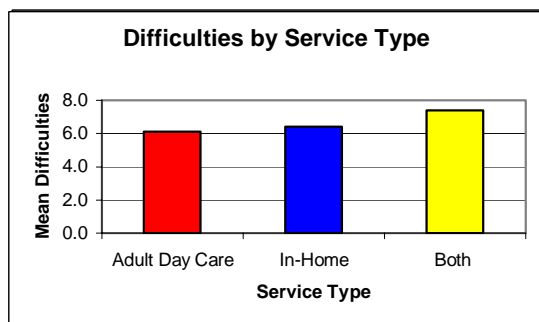
**Report**

Ethnicity	N	Mean	Std. Dev.
White	168	6.2	2.0
Black	116	6.1	2.3
Hispanic	93	8.9	3.6
Total	377	6.8	2.8

**Statistics for Difference**

Bivariate F	38.6
Incremental F	10.8
Significance Level	$p < .01$
Source of Difference: Hispanic > White and Black	

**Figure 1.18. Service Type Differences in Communication Difficulties**



**Questionnaire Items:**

1. When the respite workers discuss my [relative]'s health and care needs with me, they use words I understand.
2. How easy is it for you to talk with the respite workers?
3. When talking with the respite worker, how difficult is it to explain what help you want?
4. Workers at the respite program speak your language.

**Report**

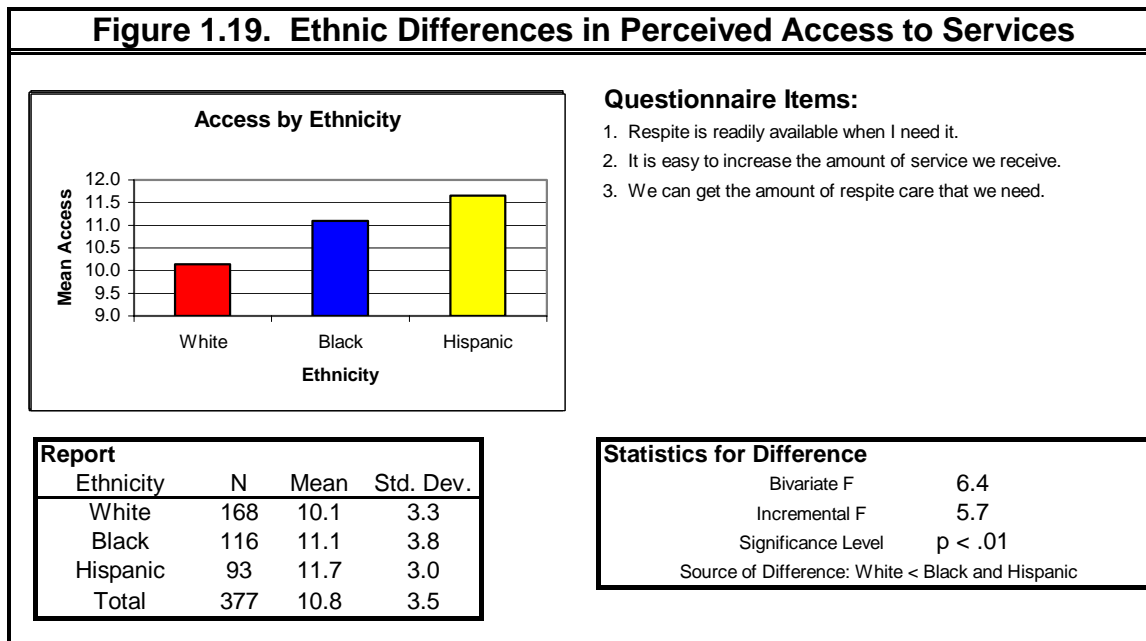
Service Type	N	Mean	Std. Dev.
Adult Day Care	143	6.1	2.1
In-Home	139	6.4	2.1
Both	52	7.4	3.5
Total	334	6.8	2.8

**Statistics for Difference**

Bivariate F	27.5
Incremental F	12.4
Significance Level	$p < .01$
Source of Difference: Both > Adult Day and In-home	

### ***The Importance of Culture***

Caregivers' beliefs and attitudes, as well as their views of services, reveal cultural differences. Members of different ethnic, geographic, and relationship groups hold markedly different beliefs about family relationships and responsibilities for care. Respite services are also perceived differently based upon type of service used and ethnicity, although the role of culture is less significant. These differences demonstrate the need for providers to consider cultural issues when developing respite programs to better address the needs of their target populations.



## CLIENT SATISFACTION WITH RESPITE SERVICES

### Overview

The final analyses for this study assessed the links between **caregiving beliefs and attitudes** and **client satisfaction** and between **clients' views of aspects of services** and **client satisfaction** (i.e., the two right-hand arrows depicted in Figure 1.1). Initially zero-order correlations between client satisfaction and the each of the two sets of attitude measures were examined. Findings from these initial analyses were then used to guide the development of parsimonious models for client satisfaction using multiple regression procedures. Separate models were tested for each type of respite program.<sup>1</sup>

### The Relationship Between Attitudes/Beliefs About Caregiving and Client Satisfaction

Zero-order correlations between the overall measure of client satisfaction and the 11 measures of caregivers' attitudes and beliefs about caregiving are reported in Table 1.14. As shown, seven of the measures of beliefs and attitudes about caregiving had correlations with satisfaction that were statistically significant. These measures included: (1) obligation, (2) family values, (3) desired amount of social contact, (4) government assistance, (5) satisfaction with help, (6) strength of religious beliefs, and (7) support from one's religious congregation.

Based upon these findings the measure of overall client satisfaction was regressed on this set of seven variables using Ordinary Least Squares (OLS) regression procedures. Separate analyses were conducted for the two types of respite and findings are reported in Tables 1.15 and 1.16.<sup>2</sup>

### *Caregiving Beliefs as Predictors of Satisfaction with ADC*

Two variables had significant, unique effects on client satisfaction in the model for day care clients: (1) as the number of desired social contacts increased, so did client satisfaction; and (2) as the amount of comfort and support from the caregiver's religious congregation increased, so did satisfaction.

**TABLE 1.14. CORRELATIONS FOR CAREGIVING ATTITUDES and BELIEFS**

<b>Affection</b>	.086	(N=332)
<b>Obligation</b>	.220*	(N=331)
<b>Family Values</b>	.192*	(N=347)
<b>Respect</b>	.078	(N=358)
<b>Social Contact</b>	.152*	(N=355)
<b>Guilt</b>	.063	(N=359)
<b>Government Assistance</b>	.114*	(N=353)
<b>Satisfaction w/ Help</b>	.262*	(N=327)
<b>Religiosity</b>	.031	(N=364)
<b>Strength of Beliefs</b>	.121*	(N=365)
<b>Support from Congregation</b>	.126*	(N=356)

\*  $p < .05$

Note: The correlations are based on listwise deletion. The substantive results are unaffected when EM imputation is used for missing data.

The fact that caregivers who desired more social contact also had higher levels of client satisfaction suggests that ADC may perform a social function. That is, Adult Day Care programs may afford caregivers an opportunity for social contact— either directly by setting the occasion for interaction with respite workers, or indirectly by allowing the caregiver to use the time off afforded by respite to find outside sources for interaction. The finding that caregivers who found emotional support from their congregation were also more satisfied with ADDGS respite services is difficult to interpret. One possibility is that this relationship is due to the implicit approval for the use of such services by an important social group. Such approval may reduce the social stigma or sense of personal failure that may accompany the use of formal services, thus raising the user's satisfaction with those services. An alternate explanation is that day care centers are similar to congregations in that workers and, perhaps family members of other clients, serve as an emotional support network.

**TABLE 1.15. REGRESSION OF CLIENT SATISFACTION ON CAREGIVING ATTITUDES and BELIEFS (ADC users only)**

	<b>b/SE</b>	<b>Beta</b>	<b>t-Value</b>	<b>Probability</b>
Obligation to Care	0.38/0.22	0.14	1.72	0.09
Family Values	0.12/0.11	0.09	1.04	0.30
Social Contact	2.06/0.77	0.21	2.69	0.01
Government Assistance	0.46/0.33	0.11	1.40	0.17
Satisfaction with Help	0.47/0.33	0.11	1.41	0.16
Strength of Beliefs	0.01/0.41	0.02	0.25	0.81
Support from Congregation	0.85/0.25	0.30	3.46	0.00
<b>F Statistic</b>		<b>5.839</b>		
<b>R<sup>2</sup></b>		<b>0.23</b>		
<b>Degrees of Freedom</b>		<b>7</b>		

**TABLE 1.16. REGRESSION OF CLIENT SATISFACTION ON CAREGIVING ATTITUDES and BELIEFS (In Home users only)**

	<b>b/SE</b>	<b>Beta</b>	<b>t-Value</b>	<b>Probability</b>
Obligation to Care	0.34/0.20	0.15	1.72	0.09
Family Values	0.31/0.14	0.20	2.20	0.03
Social Contact	-0.12/0.85	-0.01	-0.15	0.88
Government Assistance	0.03/0.38	0.01	0.09	0.93
Satisfaction with Help	0.93/0.38	0.21	2.44	0.02
Strength of Beliefs	0.70/0.40	0.16	1.76	0.08
Support from Congregation	-0.33/0.24	-0.13	-1.42	0.16
<b>F Statistic</b>		<b>4.09</b>		
<b>R<sup>2</sup></b>		<b>0.18</b>		
<b>Degrees of Freedom</b>		<b>7</b>		

***Beliefs as Predictors of Satisfaction with In-home Respite***

Two indicators of caregiver beliefs also had statistically significant correlations with client satisfaction among in-home respite users: (1) as satisfaction with outside help (i.e., the amount of instrumental and emotional support received from others) increased, so did satisfaction with the ADDGS program; and (2) as the importance placed on family values by caregivers increased, so did satisfaction with the ADDGS program. Since clients who use in-home respite are generally caring for more impaired elders, instrumental support is probably the most important type of support they can receive. Hence, it has the strongest relationship to satisfaction. Also, since the respite service is performed in the caregiver's own home, the focus on family values makes intuitive sense. Care provided in the home by a respite worker will be evaluated more highly to the extent that the caregiver views it as similar to the care that he or she would provide.

**Client Views of Aspects of Service Delivery and Client Satisfaction**

The zero-order correlations between client satisfaction and caregiver's views about aspects of service delivery are shown in Table 1.17. All eight of the measures of clients' views about aspects of service delivery had significant correlations with the measure of client satisfaction. However, the magnitude of the correlations between client satisfaction and shared values (.75) and between client satisfaction and trust (.72) indicated that the two factors are empirically indistinct from the measure of client satisfaction. Because shared values and trust are essentially an alternate measure of the same construct the two variables were dropped from the subsequent multivariate analyses.<sup>3</sup>

As before, the models for ADC and in-home were analyzed separately. This was done because the model for ADC was altered to include the variable "appropriate activities". This variable was included because it had a significant zero-order correlation with client satisfaction. However, the information was only obtained from caregivers using day care programs (See Table 1.17).<sup>4</sup>

**TABLE 1.17. CORRELATIONS FOR ASPECTS OF SERVICE DELIVERY  
and CLIENT SATISFACTION**

<b>Communication</b>	-.316*	(N=363)
<b>Expectations</b>	.603*	(N=342)
<b>Access to Services</b>	.419*	(N=331)
<b>Friendliness</b>	.630*	(N=360)
<b>Shared Values</b>	.747*	(N=304)
<b>Redtape</b>	-.400*	(N=297)
<b>Trust</b> (In Home Users only)	.724*	(N=272)
<b>Appropriate Activities</b> (ADC Users only)	.586*	(N=223)

\*  $p < .05$

Note: Correlations were calculated using listwise deletion for missing data. The substantive findings remain unchanged when estimated values are imputed for missing data.

### ***Client Views of ADC Services and Satisfaction***

Findings from the analysis for ADC are shown in Table 1.18. Three variables exerted a statistically significant, unique effect on client satisfaction: caregiving expectations, appropriateness of activities, and the amount of red tape. Specifically, when caregivers had a clear idea of what the day care workers would and would not do, client satisfaction increased. Similarly, as the perceived appropriateness of the day care activities increased, satisfaction increased as well. In contrast, as the amount of red tape associated with using the day care program decreased, satisfaction with the program increased.

**TABLE 1.18. REGRESSION OF CLIENT SATISFACTION ON  
ASPECTS OF SERVICE DELIVERY (ADC Users Only)**

	<b>b/SE</b>	<b>Beta</b>	<b>t-Value</b>	<b>Probability</b>
<b>Respite Activities</b>	1.00/0.32	0.30	3.11	0.00
<b>Clear Expectations</b>	0.81/0.32	0.23	2.53	0.01
<b>Access to Services</b>	0.09/0.18	0.04	0.52	0.60
<b>Staff Friendliness</b>	0.51/0.44	0.09	1.17	0.24
<b>Redtape</b>	-0.62/0.20	-0.28	-3.05	0.00
<b>Language Difficulties</b>	-0.10/0.41	-0.02	-0.25	0.80
<b>F Statistic</b>		<b>26.68</b>		
<b>R<sup>2</sup></b>		<b>0.54</b>		
<b>Degrees of Freedom</b>		<b>6</b>		

### ***Client Views of In-Home Services and Satisfaction***

The multivariate model evaluating the relationship between clients' satisfaction and views of various aspects of service delivery for in-home respite is shown in Table 1.19. Three of the five variables exerted a statistically significant, unique effect on client satisfaction: caregiving expectations, access to services, and friendliness of the respite worker. As in the case of ADC, when caregivers had a clear idea of what the respite workers would and would not do, client satisfaction with the service was higher. Similarly, when the service was more accessible to caregivers (e.g., available at times it was most needed), satisfaction was higher. Also, as the friendliness of the in-home worker increased, satisfaction increased as well.

### **Final Models of Client Satisfaction with ADC and In-Home Respite**

#### ***Predictors of Client Satisfaction with ADC***

In the final analyses of predictors of client satisfaction for each type of respite program, all of the significant predictors of client satisfaction were included in the model.<sup>5</sup> The final model tested for satisfaction with adult day care included two variables reflecting attitudes and beliefs about caregiving (***social contacts*** and ***support from the caregiver's religious congregation***) and three variables pertaining to client views of aspects of service delivery (***caregiver***

**TABLE 1.19. REGRESSION OF CLIENT SATISFACTION ON ASPECTS OF SERVICE DELIVERY (In Home Users Only)**

	<b>b/SE</b>	<b>Beta</b>	<b>t-Value</b>	<b>Probability</b>
<b>Clear Expectations</b>	1.34/0.32	0.29	4.17	0.00
<b>Access to Services</b>	0.49/0.15	0.20	3.20	0.00
<b>Staff Friendliness</b>	2.57/0.42	0.43	6.06	0.00
<b>Redtape</b>	-0.10/0.16	-0.05	-0.67	0.51
<b>Language Difficulties</b>	-0.22/0.31	-0.05	-0.71	0.48
<b>F Statistic</b>		<b>33.78</b>		
<b>R<sup>2</sup></b>		<b>0.56</b>		
<b>Degrees of Freedom</b>		<b>5</b>		

**expectations, amount of red tape, and perceived appropriateness of caregiving activities).**

The final model for client satisfaction with adult day care shown in Table 1.20 explained 57% of the variance in satisfaction. Four of the five variables exerted statistically significant, unique effects on client satisfaction with Adult Day Care. Satisfaction with adult day care increased as the support and comfort received from one's religious congregation increased, when caregivers had a clear idea of what the respite workers would and would not do, when the respite service was more accessible to caregivers (e.g., available at times it was most needed), or when the amount of red tape went down.

#### ***Predictors of Client Satisfaction with In-Home Respite***

The final model tested for satisfaction with in-home respite included two measures of attitudes and beliefs about caregiving (***satisfaction with the amount of help or support received from others*** and ***importance placed on family values by caregivers***) and clients views on three aspects of service delivery (***caregiver expectations, access to services, and friendliness of staff***).

**TABLE 1.20. FINAL MODEL OF CLIENT SATISFATION**  
(ADC Users Only)

	<b>b/SE</b>	<b>Beta</b>	<b>t-Value</b>	<b>Probability</b>
<b>Clear Expectations</b>	0.86/0.30	0.24	2.85	0.01
<b>Social Contact</b>	0.22/0.58	0.02	0.38	0.71
<b>Support from Congregation</b>	0.44/0.18	0.15	2.55	0.01
<b>Redtape</b>	-0.80/0.14	-0.37	-5.61	0.00
<b>Respite Activities</b>	0.95/0.30	0.26	3.20	0.00
<b>F Statistic</b>		<b>36.12</b>		
<b>R<sup>2</sup></b>		<b>0.57</b>		
<b>Degrees of Freedom</b>		<b>5</b>		

**TABLE 1.21. FINAL MODEL OF CLIENT SATISFATION**  
(In Home Users Only)

	<b>b/SE</b>	<b>Beta</b>	<b>t-Value</b>	<b>Probability</b>
<b>Clear Expectations</b>	1.43/0.31	0.31	4.62	0.00
<b>Satisfaction with Help</b>	0.23/0.27	0.05	0.85	0.40
<b>Family Values</b>	0.03/0.10	0.02	0.30	0.77
<b>Access to Services</b>	0.48/0.15	0.20	3.30	0.00
<b>Staff Friendliness</b>	2.69/0.41	0.45	6.55	0.00
<b>F Statistic</b>		<b>35.81</b>		
<b>R<sup>2</sup></b>		<b>0.57</b>		
<b>Degrees of Freedom</b>		<b>5</b>		

The final model of client satisfaction with in-home respite is shown in Table 1.21. The set of five covariates explained 57% of the variances in client satisfaction. Three variables exerted statistically significant, unique effects on client satisfaction: caregiving expectations, access to services, and friendliness of staff. As the level of each of these factors increased, so did client satisfaction with in-home respite.

### **Discussion and Implications for Service Delivery**

#### ***Effect of Culture on Client Satisfaction***

The purpose of Study One was to evaluate the role of culture in relation to client satisfaction. For this study, culture was defined in terms of three variables: ethnicity, family relationship, and geographic location. In theory, culture can affect client satisfaction either directly or indirectly through the two sets of intervening variables shown in Figure 1.1. Findings from this study, however, indicate no discernible direct effect in the present data. Nor, strictly speaking, is there a discernible indirect effect of culture on client satisfaction.<sup>6</sup> That is not to say that findings, that the two sets of intervening variables (1) caregiving beliefs and attitudes, and (2) clients' views of aspects of services are unimportant. Rather, the findings suggest that many of these variables influence client satisfaction and that service providers can profit greatly from these understandings regardless of the cultural background of the client populations that they serve.

#### ***Adult Day Care***

Perhaps the most significant finding from this study of client satisfaction is that many of the important predictors of client satisfaction are factors that are actually under the control of practitioners. In the final model for ADC (Table 1.20), three such factors had significant, unique effects on satisfaction: (1) providing a clear understanding to caregivers about what the day care program will and will not do in the way of providing care for the individual with AD; (2) reducing the amount of red tape for caregivers associated with using the day care program; and (3) providing day care activities that caregivers believe to be appropriate for their family members.

These findings suggest a number of direct avenues for program modification that day care providers might consider in order to maximize client satisfaction. First, adult day care programs

will need to be clearly specified in terms of what caregivers can expect and cannot expect from the program. Day care workers will need to be trained to convey to the caregiver clearly and unambiguously exactly which services will be provided and which will not be provided. Second, the amount of red tape matters. Things that make the service difficult to use will lower satisfaction. These barriers include waiting to see a staff member, difficulty in making an appointment with staff, and lack of flexibility in the times that the services are offered. Third, day care providers must pay attention to programming. Although professional caregivers are trained to know what caregivers “need,” caregivers have strong feelings about what constitutes appropriate care for their family member. Service providers would be wise to find out about the attitudes of caregivers concerning what is appropriate for their family member. Such information can be used directly by providers either to change programming, to educate caregivers (i.e., attitude change) concerning therapeutic activities, or some combination of both approaches, to ultimately enhance client satisfaction.

The remaining predictor of satisfaction with adult day care, support from one’s religious congregation, while not under the direct control of providers, may offer useful insights as well. One’s religious congregation is not only a source for one’s personal value system, but it also serves as a source for emotional support and social validation for one’s activities. Clearly, to the extent that the use of adult day care is consistent with one’s personal values, and is supported by one’s religious congregation, it is likely to be more valued and thereby produce greater satisfaction with the service. Religious congregations thus offer a potentially important resource and point of intervention (e.g., information and outreach in the community) for day care providers.

**In-Home Respite.** The final model of client satisfaction with in-home respite (Table 1.21) offers similar opportunities for service providers. In the case of in-home respite, all three significant predictors of client satisfaction are factors over which service providers have direct control: (1) clear expectations; (2) access to services; and (3) staff friendliness.

Again, each of these findings suggests a possible avenue for program modification that in-home respite providers might consider in order to maximize client satisfaction. First, as with ADC, it is important for providers of in-home programs to clearly specify to caregivers the exact nature of their services in terms of what caregivers can and cannot expect from the program. In-home workers will need to be trained to convey to the caregiver clearly and unambiguously exactly

which services will be provided and which will not be provided. Second, access to services is critical. Access is characterized by three features: having services available when they are needed; increasing the amount of service as needed; and generally getting the overall amount of assistance that families feel they need. The lesson is clear. Programs with arbitrary, uniform guidelines based on a “one size fits all” philosophy of care are unlikely to fit the needs of many caregivers and, consequently, result in less satisfied clients. For example, many respite programs have policies that arbitrarily limit the amount of respite that a family can use. The present findings suggest that program flexibility and responsiveness in meeting individual family respite needs is key to developing a successful service. A program that empowers caregivers in making care decisions and attends to caregivers’ perceptions of how much respite they think they will need, and when they believe they will need it, will likely have more satisfied clientele. Third, friendliness of staff is clearly important. Programs, especially in-home programs, will want to make a point to create friendly and caring relationships.

## ENDNOTES

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<sup>1</sup> Before any analyses could be performed, two methodological issues had to be addressed. First, even though the amount of missing data on individual questionnaire items was generally quite small, the use of composite indicators substantially elevated the likelihood that any given respondent would be missing at least some information across all of the relevant questions. As a result, listwise deletion of missing data was very inefficient and resulted in an unacceptable loss of information. To retain all available data, missing values were imputed using the expectation maximization (EM) algorithm (Little and Rubin, 1989) in the multivariate analyses. This procedure has been shown to be less biased than either listwise or pairwise deletion under varying assumptions about the mechanisms responsible for item nonresponse (Arbuckle, 1996). Using this imputation procedure requires that statistical tests be interpreted cautiously due to a slight downward bias in estimates of standard errors. This occurs because the imputed values are optimal statistical estimates of the missing data. As a result, they lack the residual variability present in the observed data (Enders, 2001). The statistical tests also overestimate the true sample size and resultant degrees of freedom.

Second, as is the case with most measures of client satisfaction, the present measures were highly skewed. That is, most respondents were generally very satisfied with the services they received. A cubic transformation of the satisfaction composite provided suitable relief for non-normality in the dependent variable. This variable was then divided by a constant of 100 for ease of scaling in the regression coefficients.

<sup>2</sup> An analysis was conducted to determine whether the relationships between caregivers' level of satisfaction and the seven predictor variables differed according to the type of respite program used. For this analysis, the sample was restricted to only clients who used either day care or in-home care ( $n=282$ ) to eliminate the potential for ambiguity of interpretation of effects for this analysis. Persons who used both services were excluded. To test for differences in models for the two types of services, a dichotomous variable representing type of respite services was added to the base model along with a set of seven interaction terms. The set of interactions explained an additional 6% of the variance in client satisfaction ( $F(7,266) = 2.8$ ;  $p < .01$ ) indicating that separate regression models for satisfaction with ADC and In-home respite would be more informative.

<sup>3</sup> When the correlation coefficients for shared values and trust were corrected for attenuation or measurement error (Nunnally, 1978), these estimated correlations increase to .86 and .92, respectively. The magnitude of these "corrected" correlations suggests that "shared values" and "trust" are empirically indistinct from client satisfaction (i.e., they all measure the same underlying factor). Consistent with this view is the fact that the correlation between shared values and trust is .69. When corrected for attenuation, this correlation increases to .85. Given this pattern of relationships, it is hard to escape the conclusion that shared values, trust, and client satisfaction are all measuring the same thing. Therefore, shared values and trust were dropped from the subsequent multivariate analyses.

Additional support for this decision is provided by Dutka (1994) who points out that passive performance attributes that do not measure specific, actionable characteristics

are often highly related to customer satisfaction, not because improvements relating to these attributes will increase satisfaction, but rather because passive attributes are really just alternative measures of client satisfaction. For example, in the case of shared values, the caregiver may think: "If the respite service cares for my relative the way I do, then it must be good." In this sense, shared values may represent an alternative measure of client satisfaction, since perceptions of "quality" are frequently used to define and measure "satisfaction" (e.g., Hayes, 1992). The same logic applies to the notion of trust. That is, the two constructs, shared values and trust, differ from the other aspects of service delivery in that they are "passive" attributes of the respite service. Unlike the other aspects of service delivery in Table 1.17, shared values and trust are not under the direct control of the service providers. (See also the discussion in Appendix 1D).

<sup>4</sup> When a set of interactions terms was added to the model to test for significant differences in the models for the two types of services, the added 1.5% of explained variance was not significant ( $F(5,270) = 1.71; p = .13$ ). It is therefore important to recognize that the separate models were required because the models were specified differently (i.e., the model for ADC included an extra variable – appropriate activities), **not** because the variables operated differently on satisfaction with ADC versus in-home respite.

<sup>5</sup> Two points should be noted with respect to the final models of client satisfaction with ADC and in-home respite. First, the proportion of explained variance (.57 in both models) is fairly large. Although the magnitude of explained variance suggests very good fitting (i.e., well-specified) models, it is necessary to keep in mind that multiple regression is an optimization procedure that is designed to maximize r-square within the sample. If another sample of caregivers were drawn, there is no guarantee that the same results would be obtained. Thus, these results must be interpreted with the usual amount of caution and replication is clearly desirable.

Second, the covariates of client satisfaction have been characterized as "predictors" of satisfaction. Strictly speaking, whether a given variable is most appropriately interpreted as a cause of client satisfaction or as the result of such satisfaction is an issue that cannot be resolved with cross-sectional data. The findings of this study are based on a particular set of assumptions regarding the causal relationships between certain factors and client satisfaction (see Appendix 1D). In the absence of experimental data, these assumptions can never be completely evaluated. As a result, respite providers will want to evaluate any program modifications periodically to ensure that they are having their intended effect.

<sup>6</sup> The total indirect effect of a variable is the difference obtained once the direct effect of the variable (i.e., ethnicity, family relationship, and geographic location) has been subtracted from its correlation coefficient with the outcome variable (i.e. client satisfaction; see Kerlinger and Pedhazur, 1973). None of these relationships was statistically different from zero. In other words, since the zero-order correlations were approximately zero, and the direct effects were approximately zero, the indirect effect of culture on client satisfaction in the present data are necessarily negligible as well.

# **PROFILES OF RESPITE USE**

## **STUDY TWO**

## EXECUTIVE SUMMARY

### STUDY TWO:

#### IDENTIFICATION OF PROFILES OF RESPITE SERVICE USE

##### OBJECTIVES

The goal of this study was to describe common patterns of respite use among a diverse sample of families caring for elders with dementia. These profiles are potentially useful planning tools for policy makers and service providers responsible for implementing effective and efficient respite programs. The analyses capitalized on the unique longitudinal qualities of the data from the Alzheimer's Disease Demonstration Grant to States project (ADDGS) and the diversity of the study sample.

##### METHODS

Data were gathered from 4,369 client families and 122 service providers who participated in the ADDGS demonstration in the District of Columbia, Florida, Maine, Michigan, North Carolina, South Carolina, and Washington. Information about demographic and functional status of elders and caregivers was gathered as part of the client intake process. Data pertaining to clients' use of services were taken from providers' records. Telephone interviews were conducted with key staff members to obtain programmatic information from the 122 agencies providing respite services in day care and in-home settings. Multivariate and multi-level data analysis techniques were used to analyze the longitudinal data and create profiles of respite use.

##### FINDINGS

***Almost one third of the demonstration clients used respite services for only one or two months and the mean length of use was ten months.*** White clients were most likely to be brief users. Black/African-Americans were least likely to be brief term users of day care and Hispanic/Latino clients are least likely to be brief users of in-home. This pattern may reflect the success of the ADDGS demonstration with promoting programs that effectively serve traditionally under-served populations.

***The decision by clients to continue or discontinue use of services was related to characteristics of the service providers.*** The positive relationship observed between brief user status and problem

behaviors likely reflects the limited capacity of day care providers to care for persons with problem behaviors. As long as elders were able to function in a day care setting, they continued to use that service. When elder impairment became too high, families were likely to seek in-home services. Day care was most often used as a support system when caregivers needed to be away from home or when caregivers had other obligations that required their attention. When the impairment level of the elder increased to higher levels, adult children who could not leave a parent home alone were more likely to cease caregiving.

Brief users of in-home respite appeared to constitute a sub-population of caregivers with unmet needs who had a greater need for professional health and household assistance. Consequently they tended to discontinue use of programs that were staffed by volunteers that did not provide health related services and that often did not have set fee structures.

***To fully capture variations in patterns of respite use, it was important to examine multiple measures of use including duration, continuity, and intensity of respite use.*** For extended users of respite, mean duration of service use was 16.2 months for day care clients and 14.9 months for in-home use. Day care clients used twice as many hours of service each month (50.3 versus 24.6) and almost three times (817 versus 283) as many hours of care over their full duration of service use.

***Client characteristics were the primary predictors of the duration, continuity, and intensity of service used.***

- Persons with high levels of IADL impairment used day care services for a shorter duration, but with greater intensity. Among users of in-home respite, higher levels of ADL impairment and problem behaviors were associated with more intense use of services. For users of both types of services, the number of hours of service used each month increased with duration.
- Clients assisted by a spouse were more frequent users of in-home respite programs, but they used significantly fewer hours of respite each month than did their peers who were cared for by adult children or other more distant relatives. Elders with male caregivers used more respite services.
- Different ethnic groups had distinct trajectories of day care use over time. Compared to Whites, Blacks/African-Americans tended to use smaller quantities of service over a more extended period of time. Hispanic/Latino elders used high quantities of service for shorter periods. Notably, the two

groups of minorities did not differ in the average total number of hours of day care use.

- Middle-income elders were the highest users of in-home services. For this client group in-home respite was probably the most economical solution for long term care because of limited discretionary money and ineligibility for Medicaid as a source of payment for nursing home care.

***Two provider characteristics influenced the intensity of respite service use over time.*** Families who sought respite from programs that offered a health care component used services more intensely. This trend likely reflected the higher levels of elder need. In general, clients used services more intensely when the maximum limit for services was higher, although they did not necessarily use more services over the duration of their use. This pattern suggests that arbitrary caps on services may impede effective distribution of resources among clients with different levels of need.

## PRACTICE IMPLICATIONS

Accurate cost estimates for respite services cannot be made without clear knowledge of client variations in the duration, continuity, and intensity of respite use. When providers plan and budget for respite services it is useful for them to consider the characteristics of their client population, which are directly linked to variations in patterns of use.

It is important to offer multiple forms of respite to meet the needs of different segments of the client population and to provide support for families, as needs change over time.

When designing respite services, attention should be given to both the level of care provided and the type of respite services offered.

Limitations placed by providers on the number of hours of service available to clients are likely to create significant barriers to service use if they are not appropriately tailored to match client characteristics.

## STUDY TWO:

### IDENTIFICATION OF PROFILES OF RESPITE SERVICE USE

#### INTRODUCTION

##### Purpose

The goal of this study is to provide initial answers to questions about patterns of respite use by describing the common long term profiles of use among a diverse sample of families. Despite the limited availability of empirical evidence supporting the benefits of respite, practitioners have gone forward with the development and implementation of respite programs. However, currently little practical information available to help providers plan and execute programs in an efficient manner. The simple fact is that very little is known about how caregivers actually use respite in their everyday lives.

Thus, there is a need for basic information about patterns of respite use. In a real life setting, how much respite will a family use? Over what period of time do families use respite and at what level of intensity? Are there differences in use patterns associated with the relationship of the caregiver to the elder, (i.e. spouse versus adult child)? Are patterns of service use associated with disability level of the elder, geographic regions, or cultural backgrounds of families? How do patterns of use differ for different types of respite programs (day care or in-home)? How do constraints in respite availability alter patterns of use? Answers to these questions would allow policy makers and service providers to make informed decisions about respite funding and program development.

##### Factors Likely to Influence Respite Utilization

The diversity of caregivers and their caregiving contexts is now well established by a large body of research conducted over the past two decades. This current study was undertaken with the expectation that diversity among caregivers and their contexts would likely be reflected in patterns of respite use. Specifically, three sets of variables were investigated as plausible factors affecting patterns of service use: cultural differences, differing caregiving careers, and service availability.

### ***Cultural Differences***

An abundance of studies have documented great variation in the quantity, intensity, and continuity of care that is provided by family members. *Patterns of family care have been linked to the ethnic background of the family, the geographic location of the family, and the familial relationship of the caregiver to the elder (i.e. spouse, child, or other family member).* (See Study One for a further discussion.) Although the level or type of impairment of the elder may determine the need for care decisions, the *type* of care that is provided, the *specific individual* provides the care, and the *manner* in which it is provided are largely influenced by characteristics of the caregiver. It was therefore reasonable to assume that patterns of respite use are also linked to these differences in caregiving contexts.

### ***Caregiving Careers***

Another important aspect of informal caregiving is its dynamic nature. Caregiving has been likened to a career of variable length (Montgomery and Kosloski, 2000; Pearlin et al., 1990; Zarit, 1993). As such, the caregiving history for each person has (1) a beginning, (2) some definable temporal extension or duration, and (3) an end or resolution (e.g., recovery, death or nursing home placement). Although the caregiving process or career can be described in temporal units, time is unlikely to be an adequate descriptor. Hence knowing, for example, that a caregiving relationship has existed for 12 months does not provide much useful information about the specific needs of a given family, their prospects for continued caregiving, nor their use of respite services. There is a great deal of individual variation in the trajectory of caregiving careers. This variation has been shown to be related to a number of demographic and attitudinal characteristics of the caregiver and the care receiver (See Montgomery and Kosloski, 2000; Kosloski and Montgomery, 1993b; Zarit, 1993). Changes in patterns of care have also been linked with changes in elder functioning (Peek et al., 1997), caregiver functioning, and the availability of support from both informal (Gill et al., 1998; Worcester and Hedrick, 1997) and formal sources (Bass et al., 1996). The dynamic process of caregiving is also likely to affect respite use over time.

### ***Service Availability***

Obviously, respite services must be available for families to use them. Yet, like respite use, availability is not a dichotomous variable. Availability of services may be described in terms of quantity, type of service, and hours of operation. Both formal and informal criteria are used to make services available to some caregivers and not to others. Individual and family

characteristics not only influence caregivers' choices, they also influence providers' decisions about service availability. Concerned with maximizing their resources, providers make choices about hours and times of operation and they create eligibility rules for rationing and/or distributing services. Guidelines for rationing scarce resources can be formal rules such as caps or limitations on the number of hours or dollars available to different clients. Rationing can also occur in informal ways through waivers or exceptions to established caps. Such informal criteria often reflect a case manager's subjective perception of family need. Hence, program characteristics such as hours of operation, service caps, flexibility of rules, and the discretionary decision-making of case managers can also affect patterns of client use.

### **Potential Contributions of study for Policy and Practice**

The findings from this study are particularly useful because they stem from analyses of longitudinal data, which provide unique insights into long term patterns of respite use. For the most part, previous studies of respite services have been limited in scope and sample size. In the past, the limited nature of resources for large, longitudinal demonstration studies has prevented a thorough analysis of diverse patterns of respite use. However, in 1991 when Congress passed the legislation for the Alzheimer's Disease Demonstration Grants to States (ADDGS), it mandated an evaluation of the program. Although initially the ADDGS project funded for only three years, the evaluation was designed to take advantage of longitudinal data should they become available. Fortunately, the three-year demonstration project has now completed its ninth year and an extensive data set has been developed to address several important questions about caregivers' use of respite over time. As part of the mandated evaluation, longitudinal data were collected about client families and their use of support services.

The findings from these analyses will potentially benefit several groups. First, providers responsible for developing respite programs can use the findings to plan more efficiently and tailor programs to the characteristics of persons in their catchment area who are most likely to use services. Providers who already have respite programs in operation may use the information to modify service delivery of their programs and increase the benefits to users. With detailed information about current and preferred patterns of respite use for different segments of the elderly population, providers will also be able to more accurately assess the level of

community need and determine likely costs for the delivery of respite services more appropriately. Additionally, it will help providers to distribute their resources more effectively by understanding the diverse ways in which different caregivers, with different needs, use services. Thus, the arbitrary limits (service caps) providers sometimes apply may give way to more appropriate targeting and dosing of services.

Second, knowledge of the patterns of respite use identified by this analysis will be useful to policy makers and planners who must estimate the long term costs of service delivery. Very little is known about the long term use of respite by families in real community settings. The patterns observed in this study, which focused on a multitude of programs operating in a variety of communities, are likely to vary dramatically from the artificial conditions of most evaluation studies.

Third, the findings from this study will assist researchers who are attempting to answer the ultimate question of cost effectiveness. Quite frankly, there is little consistency in the definition of “respite use” in evaluation studies. By observing how respite is actually implemented and used across a wide range of programs, it may be possible to develop definitions of “respite use” that are applicable to real-life settings that can be employed in future studies.

## **STUDY DESIGN**

### **Study Questions**

Four basic questions concerning patterns of respite use among a diverse sample of families caring for an elder with dementia have been addressed:

1. What is the duration of respite use?
2. How much respite is used?
3. How consistently or continuously do families use respite?
4. Do patterns of service use change over time?

In addition to addressing the four basic questions, the analysis also focused on three questions pertaining to differences in patterns of respite use that are likely to be associated with

characteristics of families and/or providers:

5. Do patterns of respite use differ by type of respite service (e.g. in-home or day care)?
6. To what extent are patterns of respite use associated with characteristics of the caregiver or elder?
7. To what extent are patterns of respite use associated with characteristics of service providers?

### **Study Population**

Data for this study were gathered from 4,369 client families and 122 service providers who participated in the ADDGS demonstration in the District of Columbia, Florida, Maine, Michigan, North Carolina, South Carolina, and Washington. These seven states were selected for inclusion in this study because the data for these states were deemed to be most reliable and best represent the cultural diversity of the demonstration. The study population includes *all client families* from the seven states who used in-home respite or day care services provided through the ADDGS demonstration between September 1992 and December 1998. Although a broad range of support services (e.g., case management, transportation, education, support groups, and legal assistance) and respite services were provided through the ADDGS, only families utilizing in-home respite and day care services were included in the analyses for this study. Data from families using institutional and residential respite were not included because the number of families (less than 2%) using these services was too small for reliable analyses. Families qualified for participation in the demonstration if the elder showed signs of dementia; a formal diagnosis of Alzheimer's disease was not required. The 122 agencies included in the analyses were identified as the providers of services used by the 4,369 clients included in the study.

### **Client Families**

#### ***Data Collection***

Client data for this analysis were obtained from three sources. Information about demographic characteristics of the elders and caregivers as well as the functional status of elders was gathered as part of the intake process at the time of client enrollment (See Appendix 2A). Data

pertaining to clients' use of services were taken from providers' records (See Appendix 2B). Finally, to obtain information about the current care status of each client, a special query was sent to providers. Providers were asked to identify those clients who were continuing to use project services and those clients who had stopped using services. If a client no longer used the project's respite service, providers indicated whether the client had moved out of the service area, moved to a care facility, died, or continued to live within the service catchment area. When possible, providers also reported the date of death or transition to a different care source (see Appendix 2C).

### ***Client Characteristics***

As shown in Table 2.1, the largest percentage of respondents was from the state of Michigan, representing 32.7% of the sample. Families from Washington comprised the smallest segment accounting for only 5.7% of the study group. Each of the remaining five states contributed between 8.6% and 16.6% of the study population. The demonstration project was particularly

**TABLE 2.1. DISTRIBUTION OF SAMPLE**

	Number of Families	
	4369	%
<b>State</b>		
Washington D.C.	407	9.3%
Florida	725	16.6%
Maine	375	8.6%
Michigan	1429	32.7%
North Carolina	469	10.7%
South Carolina	713	16.3%
Washington	251	5.7%
<b>Service Type</b>		
Day Care	1679	38.4%
In-Home	2176	49.8%
Both services	514	11.8%
<b>Race</b>		
White	2483	56.8%
Black/African-American	1378	31.5%
Hispanic/Latino	335	7.7%
Asian/Pacific Islander	108	2.5%
Native American/Alaskan	14	0.3%
Unknown	42	1.0%
<b>Geographic Location</b>		
Urban	1760	40.3%
Rural	2331	53.4%
Unknown	278	6.4%

targeted to minority populations and rural communities. Consequently the study sample includes larger numbers of minorities and rural elders than is usual for caregiver studies. Across all sites, users of in-home respite accounted for nearly fifty percent of the sample, while day care clients comprised 38.4%. In addition to families that used one type of respite, some families accessed both types of respite services. These dual users made up 11.8% of the study sample.

Just under 57% of persons in the primary sample were White. Black/African-Americans accounted for 31.5% with Hispanic/Latinos making up slightly fewer than 8%. Individuals designated as Asian/Pacific Islander, Native American/Alaskan and unknown ethnicities comprised the remaining 4% of the sample.

More than one-half (53.4%) of all participants reported living in geographic areas classified as sparsely populated or rural. Urban dwellers (i.e., those residing in cities with populations of more than 50,000) comprised 40.3% of the sample. Data pertaining to geographic residence were not available for 6.3% of the sample.

The records of the 4369 families were used to create two data sets for separate analyses of utilization of in-home respite services and day care services. A total of 2193 cases (1679+514) were included in the day care sample and 2690 cases (2176+514) were included in the in-home sample. There were 514 (12%) families that utilized both in-home respite and day care and thus, were added to each service sub-sample.

### **Service Providers**

A total of 122 agencies from the seven sites were identified from project records as ADDGS service providers for clients included in the longitudinal sample. At the time of data collection (Fall 1999), 104 agencies were still providing respite services to demonstration clients. Eighteen agencies were either closed or no longer participating in the ADDGS but programmatic information was obtained from former directors. Thus, detailed programmatic information was obtained from 112 direct service providers. The remaining 10 agencies were providers that

operated as umbrella organizations, or portals, that directed care for clients through a variety of subcontracting agencies. Portal agencies directly provided case management activities but contracted with other agencies for respite services. As a consequence, uniform information regarding programmatic policies of day care and in-home providers was unattainable for clients served through these 10 portal agencies. Additionally, thirty-five of the 112 direct care providers offered more than one type of respite (i.e., group day and in-home). In these cases, information was gathered on each program component.

### **Collection of Provider Data**

Telephone interviews were conducted with key staff members to obtain programmatic information from the 122 agencies providing demonstration day care and in-home services. A structured data collection instrument (see Appendix 2D) was developed to gather relevant information. A copy of the data collection instrument was sent by letter or facsimile to the state coordinator of the ADDGS sites as well as to the agency service providers. Respondents were either state coordinators or direct care providers of the services. In some cases, the respondents completed the form and mailed it to the study team. Follow-up telephone calls were then made to all respondents to clarify any information that was not completely reported. For those who did not return the form, telephone interviews were completed with each agency representative to gather the needed information.

Data were collected about the following program characteristics for both day care and in-home respite services: service caps (maximum hours available), service availability, changes in caps and availability over the period of the demonstration, provider amenability to waiving caps, fee structure, type of staffing (paid/volunteer), level of care, and location. Additionally, for in-home programs, information was gathered about the availability of services during evening hours and on weekends. For day care programs, information was also obtained about hours, days of operation, and the availability of transportation.

### ***Provider Characteristics***

Table 2.2 reports provider characteristics by type of service. A total of 76 day care and 50 in-home respite providers are included in the sample. The sample only includes programs that provided direct care to clients in the sample. Programs that functioned as gateways or point of entries only, and did not provide direct services, were not included in the sample.

**TABLE 2.2 PROVIDER CHARACTERISTICS BY SERVICE TYPE**

	Day Care 76		In-Home Respite 50	
	N	%	N	%
<b>State of Location</b>				
Washington D.C.	2	2.6%	1	2.0%
Florida	10	13.2%	6	12.0%
Maine	5	6.6%	5	10.0%
Michigan	17	22.4%	12	24.0%
North Carolina	16	21.1%	12	24.0%
South Carolina	19	25.0%	9	18.0%
Washington	7	9.2%	5	10.0%
<b>Annual Service Cap (hours)</b>	mean = 792		mean = 406	
<b>Change in Service Cap</b>				
Decreased Cap	10	13.2%	10	20.0%
Increased Cap	23	30.3%	9	18.0%
No Change	43	56.6%	31	62.0%
<b>Service Availability (hours monthly)</b>	mean = 91.6			
Daytime Only			32	64.0%
Anytime			18	36.0%
<b>Change in Availability</b>				
Decreased Availability	5	6.6%	4	8.0%
Increased Availability	27	35.5%	7	14.0%
No Change	44	57.9%	39	78.0%
<b>Service Cap May be Waived</b>				
Yes	14	18.4%	19	38.0%
No	62	57.6%	31	62.0%
<b>Fee Structure</b>				
Percentage Copay	4	5.3%	5	10.0%
Set Fee Structure	10	13.2%	4	8.0%
Sliding Scale	48	63.2%	23	46.0%
Voluntary Contribution	14	18.4%	18	36.0%
<b>Staffing</b>				
All Paid	25	32.9%	31	62.0%
All Volunteer	0	0.0%	0	0.0%
Paid and Volunteer	51	67.1%	18	36.0%
Unknown	0	0.0%	1	2.0%
<b>Level of Care</b>				
Socialization/Companionship Only	40	52.6%	5	10.0%
Health/Personal Care	36	47.4%	42	84.0%
Unknown	0	0.0%	3	6.0%
<b>Transportation Provided</b>				
Yes	31	40.8%		
No	45	59.2%		
<b>Type of Day Care</b>				
Adult Day Care	39	51.3%		
Group Respite	30	39.5%		
Both	7	9.2%		

The majority of providers for both day care and in-home respite were located in Michigan, North Carolina, and South Carolina. Providers in these three states comprised approximately 20% of providers of each type of service. Only 2% of the day care providers and in-home providers were located in the District of Columbia. Providers in Florida, Washington, and Maine accounted for about 30% of the sample with between 7% and 13% of the providers of both types of service located in each of these states. It is important to note that distribution of the provider sample does not correspond to the distribution of clients across the various states because providers varied significantly in the number of clients they serve.

The annual service cap of a provider reflects the maximum number of service hours allocated to clients per year. The average annual service cap for day care agencies of 792 hours was two times greater than the average cap of 406 hours for in-home agencies. This disparity between service caps is readily explained. Since day care is typically provided in 4 to 6 hour allotments and in-home care is generally offered in 2 to 3 hour allotments, the number of instances or days of use is more comparable than is the number of hours.

Over the course of the ADDGS, service caps changed for approximately 40% of both day care and in-home agencies. Among day care programs, increased caps (30.3%) were more common than decreased caps (13.2%). However, for in-home respite, the percentage of increased caps to decreased caps was relatively the same (20.8% to 18%).

Service availability was evaluated differently for the two types of respite services due to structural differences in their delivery. In general, day care agencies maintained set hours of operation, yet the number of days and the length of time available varied dramatically across sites. As a result, availability for day care is represented by the mean number of hours. In-home respite providers typically operate on an appointment basis. Consequently, availability is more clearly represented by times of the day that clients have discretion to use service (i.e., daytime only or anytime). On average, day care agencies were open 92 hours per month. Based on a six-hour day, day care programs were available approximately 15 days a month. One-third (36%) of the in-home programs made services available at any time, while the remainder provided services only during daytime hours. The majority of agencies did not change times of service availability over the duration of the demonstration. However, when

changes did occur, availability was typically increased. The majority of respite programs did not offer waivers on service caps. Of those that did, in-home agencies were more likely to offer waivers (38%) than were day care agencies (18.4%).

Providers in the ADDGS employed four fee structures including: co-payment requirements, set fees, sliding fee scales, and voluntary contributions. The most common fee structure for both types of service was a sliding fee scale followed by voluntary contributions. Almost half (46%) of the in-home programs and almost two thirds (63.2%) of the day care programs used a sliding fee scale. The fee structure for 36% of the in-home providers and 18.4% of the day care programs was voluntary contributions. Clients were less likely to encounter requirements for co-payment or set fees. Only four (5.3%) day care providers and five (10%) in-home providers used co-pay structures. Ten (13.2%) day care providers and four (8%) in-home providers had a set fee structure.

The most common types of fee structures, sliding fee scales and voluntary contributions, are also the least distinctive in practice. Agencies that assess fees according to a sliding fee scale generally use income guidelines as a basis for these charges. Similarly, agencies employing voluntary contributions often suggest an appropriate contribution according to family income or leave the amount of the contribution to the discretion of the family. A few agency directors expressed the sentiment that when an income guideline was used to suggest voluntary contributions, most client families were strongly encouraged to make the recommended contribution. There were also a number of agencies that provided services without any charge to the demonstration clients. Across sites, providers reported considerable flexibility in assisting clients with service costs. The majority of providers reported that clients were not refused services for an inability to pay and that occasionally other funding sources were available for clients who could not make the expected minimum payment.

Respite agencies staffed their respite programs with paid workers or a combination of paid workers and volunteers. No providers reported using only volunteer staff. Volunteers were much more likely to be working for day care centers than for in-home agencies. Approximately two-thirds (67.1%) of the day care agencies in this sample were staffed by a combination of paid and volunteer workers. Conversely, only one-third (36%) of in-home agencies employed both

paid and volunteer staff.

Respite agencies in this sample also offered differing levels of physical care. Just over half (52.6%) of the day care programs limited care to socialization or companionship. The remaining 36 (47.4%) programs provided health related services. In contrast, the large majority (84%) of in-home programs offered health care and personal care services. Only five (10%) of the in-home providers limited their services to socialization or companionship.

Approximately 40% of the day care providers in the sample provided transportation services to their clients. Just over half of the day care programs offered full-day (six or more hours) services three or more days per week. These programs were categorized as *adult day care programs*. Thirty (39.5%) of the day care respite programs were categorized as *group day respite programs* because they provided services that were limited in scope to three to four hours of services one or two days per week. Seven (9.2%) of the providers offered both types of day care programs.

### **Strategy for Data Analysis**

Two sets of analyses were conducted to fully describe the patterns of respite use by clients. The first set of analyses focused on clients who used services for only a brief period. These analyses included all clients who limited their use of respite services to one or two months. Both descriptive statistics and logistic regression techniques were used to identify key characteristics of these brief users. The second set of analyses focused on clients who used services for three or more months. Regression techniques and hierarchical linear modeling procedures were used to identify and describe their patterns of respite use.

Of the 2193 clients using day care services, 640 were brief users and 1553 were extended users. Key characteristics of day care users are shown on Tables 2.3 and 2.4. Of the 2690 clients using in-home services 831 were short term users and 1859 were extended users. Characteristics of elders and caregivers using in-home services are shown in Tables 2.5 and 2.6.

**TABLE 2.3 DAY CARE: ELDER CHARACTERISTICS**

	<b>All Daycare Users</b>		<b>Brief Users</b>		<b>Extended</b>	
	<b>2193</b>	<b>100%</b>	<b>640</b>	<b>29.2%</b>	<b>1553</b>	<b>70.8%</b>
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
<b>*Race</b>						
White	1111	50.7%	377	58.9%	734	47.3%
Black/African-American	722	32.9%	159	24.8%	563	36.3%
Hispanic/Latino	244	11.1%	67	10.5%	177	11.4%
Asian/Pacific Islander	83	3.8%	25	3.9%	58	3.7%
Native American/Alaskan	6	0.3%	3	0.5%	3	0.2%
Unknown	5	0.2%	9	1.4%	18	1.2%
<b>*Geographic Location</b>						
Urban	1046	47.7%	283	44.2%	763	49.1%
Rural	1002	45.7%	318	49.7%	684	44.0%
Unknown	145	6.6%	39	6.1%	106	6.8%
<b>Average Income</b>						
Under \$5,000	331	15.1%	89	13.9%	242	15.6%
\$5,000 - \$15,000	1255	57.2%	361	56.4%	894	57.6%
\$15,001 - \$30,000	319	14.5%	101	15.8%	218	14.0%
\$30,001 - \$50,000	50	2.3%	15	2.3%	35	2.3%
Over \$50,000	18	0.8%	5	0.8%	13	0.8%
Unknown	220	10.0%	69	10.8%	151	9.7%
<b>Gender</b>						
Male	734	33.5%	232	36.3%	502	32.3%
Female	1410	64.3%	396	61.9%	1014	65.3%
Unknown	49	2.2%	12	1.9%	37	2.4%
<b>Marital Status</b>						
Single/Divorced	124	5.7%	33	5.2%	91	5.9%
Married	832	37.9%	264	41.3%	568	36.6%
Widowed	1085	49.5%	299	46.7%	786	50.6%
Unknown	152	6.9%	44	6.9%	108	7.0%
<b>*Living Arrangement</b>						
Live Alone	277	12.6%	83	13.0%	194	12.5%
Live with Spouse	821	37.4%	265	41.4%	556	35.8%
Live with Children	827	37.7%	218	34.1%	609	39.2%
Other	233	10.6%	57	8.9%	176	11.3%
Unknown	35	1.6%	17	2.7%	18	1.2%
<b>*Total Number in Household</b>						
Live Alone	277	12.6%	83	13.0%	194	12.5%
Elder + 1 other	953	43.5%	303	47.3%	650	41.9%
Elder + 2 others	423	19.3%	111	17.3%	312	20.1%
Elder + 3 or more	501	22.8%	124	19.4%	377	24.3%
Other/Unknown	39	1.8%	19	3.0%	20	1.3%
<b>Number of Services Used Prior to Entry</b>						
0	802	36.6%	257	40.2%	545	35.1%
1 - 2	1091	49.7%	296	46.3%	795	51.2%
3 or more	300	13.7%	87	13.6%	213	13.7%

\* Difference between the brief users and the extended group significant at  $p \leq .05$

**TABLE 2.3 DAYCARE: ELDER CHARACTERISTICS--Continued**

	<b>All Daycare Users</b>		<b>Brief Users</b>		<b>Extended</b>	
	<b>2193</b>	<b>100%</b>	<b>640</b>	<b>29.2%</b>	<b>1553</b>	<b>70.8%</b>
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
<b>Alzheimer's Disease</b>						
Suspected	385	17.6%	91	14.2%	294	18.9%
Diagnosed	1534	69.9%	464	72.5%	1070	68.9%
Other	268	12.2%	70	10.9%	183	11.8%
Unknown	6	0.3%	15	2.3%	5	0.3%
<b>Functional Level</b>						
*Mean ADL (0 - 10)	3.1		3.4		3.0	
Mean IADL (0 - 16)	12.2		12.4		12.1	
*Mean ADL/IADL (0 - 26)	15.3		15.7		15.2	
<b>Problem Behavior</b>						
*Mean Score (0 - 45)	12.9		14.1		12.5	
<b>Mean age</b>	78.8		79.3		78.6	

\* Difference between the brief users and the extended group significant at  $p \leq .05$

## BRIEF USERS

One important goal for agencies providing respite services is to provide services that are appropriate for the full range of caregivers. Most observers would agree that respite programs, especially publicly subsidized respite programs, should not systematically exclude any group of potential service users. Not surprising then, the issue of why some caregivers use respite services while others choose not to is of persisting interest to service planners, providers, and evaluators.

Just as there is no single type of "service user", non-users of respite are also of multiple types (Kosloski, Montgomery and Youngbauer, 2001). For example, there are caregivers who are unaware that such services exist. Others are aware of respite programs, but never inquire about them, nor utilize the services. There are also caregivers who might be viewed as "service seekers". These are individuals who inquire about the services, but never actually use them. Finally there are caregivers who use the services over a relatively short period of time and then, apparently, never use them again.

**TABLE 2.4 DAY CARE: CAREGIVER CHARACTERISTICS**

	<b>All Daycare Users</b>		<b>Brief Users</b>		<b>Extended</b>	
	<b>2193</b>	<b>100%</b>	<b>640</b>	<b>29.2%</b>	<b>1553</b>	<b>70.8%</b>
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
<b>Gender</b>						
Male	506	23.1%	143	22.3%	363	23.4%
Female	1595	72.7%	468	73.1%	1127	72.6%
Unknown	92	4.2%	29	4.5%	63	4.1%
<b>*Relationship to Elder</b>						
Spouse	709	32.3%	237	37.0%	472	30.4%
Adult child / child-in-law	1086	49.5%	299	46.7%	787	50.7%
Other relative	221	10.1%	62	9.7%	159	10.2%
Friend	52	2.4%	10	1.6%	42	2.7%
Professional care manager	82	3.7%	20	3.1%	62	4.0%
Self	12	0.5%	7	1.1%	5	0.3%
Unknown	31	1.4%	5	0.8%	26	1.7%
<b>Marital Status</b>						
Single/Divorced	269	12.3%	76	11.9%	193	12.4%
Married	1477	67.4%	450	70.3%	1027	66.1%
Widowed	129	5.9%	32	5.0%	97	6.2%
Unknown	318	14.5%	82	12.8%	236	15.2%
<b>Services Used</b>						
Day Care only	1679	76.6%	483	75.5%	1196	77.0%
Day Care and In-home	514	23.4%	157	24.5%	357	23.0%
<b>*Age (in years)</b>						
44 or less	317	14.5%	82	12.8%	235	15.1%
45 - 54	352	16.1%	97	15.2%	255	16.4%
55 - 64	393	17.9%	111	17.3%	282	18.2%
65 - 74	350	16.0%	102	15.9%	248	16.0%
75 - 84	274	12.5%	96	15.0%	178	11.5%
Over 84	38	1.7%	12	1.9%	26	1.7%
Unknown	469	21.4%	140	21.9%	329	21.2%
<b>*Mean age</b>	59.1		60.3		58.6	
<b>Education</b>						
Less than high school	427	19.5%	134	20.9%	293	18.9%
Completed high school	625	28.5%	182	28.4%	443	28.5%
Vocational training	115	5.2%	32	5.0%	83	5.3%
Attended college	390	17.8%	114	17.8%	276	17.8%
College graduate	379	17.3%	101	15.8%	278	17.9%
Graduate work	75	3.4%	17	2.7%	58	3.7%
Unknown	182	8.3%	60	9.4%	122	7.9%
<b>*Employment</b>						
Full-time	646	29.5%	159	24.8%	487	31.4%
Part-time	213	9.7%	54	8.4%	159	10.2%
Unemployed	494	22.5%	138	21.6%	356	22.9%
Retired	635	29.0%	217	33.9%	418	26.9%
Other	118	5.4%	40	6.3%	78	5.0%
Unknown	87	4.0%	32	5.0%	55	3.5%

\* Difference between the brief users and the extended group significant at  $p \leq .05$

**TABLE 2.4 DAYCARE: CAREGIVER CHARACTERISTICS--Continued**

	All Daycare Users		Brief Users		Extended	
	2193	100%	640	29.2%	1553	70.8%
	N	%	N	%	N	%
<b>Average income</b>						
Under \$5,000	278	12.7%	90	14.1%	188	12.1%
\$5,000-\$15,000	567	25.9%	170	26.6%	397	25.6%
\$15,001-\$30,000	475	21.7%	134	20.9%	341	22.0%
\$30,001-\$50,000	195	8.9%	52	8.1%	143	9.2%
Over \$50,000	78	3.6%	18	2.8%	60	3.9%
Unknown	600	27.4%	176	27.5%	424	27.3%
<b>Driving Distance from Elder (in minutes)</b>						
Lives in same household	1805	82.3%	517	80.8%	1288	82.9%
1 - 10	184	8.4%	52	8.1%	132	8.5%
11 - 30	109	5.0%	38	5.9%	71	4.6%
Over 30	21	1.0%	5	0.8%	16	1.0%
Other/Unknown	74	3.4%	28	4.4%	46	3.0%
<b>Length of caregiving before program entry (in months)</b>						
0 - 6	351	16.0%	91	14.2%	260	16.7%
7 - 12	220	10.0%	71	11.1%	149	9.6%
13 - 24	367	16.7%	105	16.4%	262	16.9%
25 - 36	290	13.2%	80	12.5%	210	13.5%
37 - 72	379	17.3%	96	15.0%	283	18.2%
72 or more	336	15.3%	111	17.3%	225	14.5%
Unknown	250	11.4%	86	13.4%	164	10.6%
<b>Mean length of caregiving</b>	40.0		41.5		39.4	

\* Difference between the brief users and the extended group significant at  $p \leq .05$

Knowledge about this last group of caregivers (i.e., those who are brief users) is particularly important for two reasons. First, brief users constitute a substantial proportion of all service users. Brief users have been shown to comprise from 24 to 29% of all respite users (Cox, 1997; Zarit, Stephens, Townsend, Greene and Leitsch, 1999). As such, they contribute significantly to the monthly caseload of users and consequently providers must reserve space for them. But since brief users fail to return for services, the reservation of space for them constitutes a very inefficient allocation of resources. In this study, approximately 30% of the families in the sample used respite services for two months or less. Second, and more importantly, brief users have, by their behavior, indicated a need for respite services. Whereas non-users and seekers may simply not have perceived a need for outside assistance, the same cannot be said for brief users. In fact, it is hard to escape the impression that the respite program has somehow failed these individuals. That is, since the respite service was actually tried by the caregiver and abruptly discontinued, it was apparently found lacking in some way or otherwise did not meet

**TABLE 2.5 IN-HOME: ELDER CHARACTERISTICS**

	All In-Home Users		Brief Users		Extended	
	2690	100%	831	30.9%	1859	69.1%
	N	%	N	%	N	%
<b>*Race</b>						
White	1649	61.3%	533	64.1%	1116	60.0%
Black/African-American	828	30.8%	221	26.6%	607	32.7%
Hispanic/Latino	131	4.9%	40	4.8%	91	4.9%
Asian/Pacific Islander	44	1.6%	17	2.0%	27	1.5%
Native American/Alaskan	10	0.4%	5	0.6%	5	0.3%
Unknown/other	28	1.0%	11	1.3%	13	0.7%
<b>Geographic Location</b>						
Urban	907	33.7%	276	33.2%	631	33.9%
Rural	1623	60.3%	514	61.9%	1109	59.7%
Unknown	160	5.9%	41	4.9%	119	6.4%
<b>Average Income</b>						
Under \$5,000	385	14.3%	126	15.2%	259	13.9%
\$5,000 - \$15,000	1508	56.1%	460	55.4%	1048	56.4%
\$15,001 - \$30,000	476	17.7%	138	16.6%	338	18.2%
\$30,001 - \$50,000	71	2.6%	22	2.6%	49	2.6%
Over \$50,000	20	0.7%	8	1.0%	12	0.6%
Unknown	230	8.6%	77	9.3%	153	8.2%
<b>*Gender</b>						
Male	915	34.0%	306	36.8%	609	32.8%
Female	1728	64.2%	512	61.6%	1216	65.4%
Unknown	47	1.7%	13	1.6%	34	1.8%
<b>Marital Status</b>						
Single/Divorced	123	4.6%	31	3.7%	92	4.9%
Married	1270	47.2%	393	47.3%	877	47.2%
Widowed	1153	42.9%	361	43.4%	792	42.6%
Unknown	144	5.4%	46	5.5%	98	5.3%
<b>Living Arrangement</b>						
Live Alone	426	15.8%	131	15.8%	295	15.9%
Live with Spouse	1251	46.5%	385	46.3%	866	46.6%
Live with Children	817	30.4%	255	30.7%	562	30.2%
Other	180	6.7%	54	6.5%	126	6.8%
Unknown	16	0.6%	6	0.7%	10	0.5%
<b>Total Number in Household</b>						
Live Alone	426	15.8%	131	15.8%	295	15.9%
Elder + 1 other	1442	53.6%	458	55.1%	984	52.9%
Elder + 2 others	464	17.2%	136	16.4%	328	17.6%
Elder + 3 or more	338	12.6%	99	11.9%	239	12.9%
Other/Unknown	20	0.7%	7	0.8%	13	0.7%
<b>Number of Services Used Prior to Entry</b>						
0	935	34.8%	304	36.6%	631	33.9%
1 - 2	1416	52.6%	430	51.7%	986	53.0%
3 or more	339	12.6%	97	11.7%	242	13.0%

\* Difference between the brief users and the extended group significant at  $p \leq .05$

**TABLE 2.5 IN-HOME: ELDER CHARACTERISTICS--Continued**

	<b>All In-Home Users</b>		<b>Brief Users</b>		<b>Extended</b>	
	<b>2690</b>	<b>100%</b>	<b>831</b>	<b>30.9%</b>	<b>1859</b>	<b>69.1%</b>
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
<b>Alzheimer's Disease</b>						
Suspected	434	16.1%	117	14.1%	317	17.1%
Diagnosed	2017	75.0%	648	78.0%	1369	73.6%
Other	235	8.7%	65	7.8%	170	9.1%
Unknown	4	0.1%	1	0.1%	3	0.2%
<b>Functional Level</b>						
*Mean ADL (0 - 10)	4.5		4.2		4.6	
Mean IADL (0 - 16)	13.1		13.1		13.0	
Mean ADL/IADL (0-26)	17.5		17.3		17.6	
<b>Problem Behavior</b>						
Mean Score (0 - 45)	13.0		13.3		12.9	
<b>Mean age</b>	80.0		80.1		80.0	

\* Difference between the brief users and the extended group significant at  $p \leq .05$

**TABLE 2.6 IN-HOME: CAREGIVER CHARACTERISTICS**

	<b>All In-Home Users</b>		<b>Brief Users</b>		<b>Extended</b>	
	<b>2690</b>	<b>100%</b>	<b>831</b>	<b>30.9%</b>	<b>1859</b>	<b>69.1%</b>
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
<b>Gender</b>						
Male	719	26.7%	214	25.8%	505	27.2%
Female	1911	71.0%	604	72.7%	1307	70.3%
Unknown	60	2.2%	13	1.6%	47	2.5%
<b>Relationship to Elder</b>						
Spouse	1084	40.3%	341	41.0%	743	40.0%
Adult child / child-in-law	1183	44.0%	366	44.0%	817	43.9%
Other relative	276	10.3%	77	9.3%	199	10.7%
Friend	68	2.5%	24	2.9%	44	2.4%
Professional care manager	25	0.9%	11	1.3%	14	0.8%
Self	5	0.2%	0	0.0%	5	0.3%
Unknown	49	1.8%	12	1.4%	37	2.0%
<b>Marital Status</b>						
Single/Divorced	308	11.4%	92	11.1%	216	11.6%
Married	1902	70.7%	599	72.1%	1303	70.1%
Widowed	198	7.4%	65	7.8%	133	7.2%
Unknown	282	10.5%	75	9.0%	207	11.1%
<b>Services Used</b>						
In-home Only	2176	80.9%	679	81.7%	1497	80.5%
In-home and Day Care	514	19.1%	152	18.3%	362	19.5%

\* Difference between the brief users and the extended group significant at  $p \leq .05$

**TABLE 2.6 IN-HOME: CAREGIVER CHARACTERISTICS--Continued**

	All In-Home Users		Brief Users		Extended	
	2690	100%	831	30.9%	1859	69.1%
	N	%	N	%	N	%
Age (in years)						
44 or less	300	11.2%	87	10.5%	213	11.5%
45 - 54	415	15.4%	130	15.6%	285	15.3%
55 - 64	458	17.0%	141	17.0%	317	17.1%
65 - 74	520	19.3%	151	18.2%	369	19.8%
75 - 84	492	18.3%	138	16.6%	354	19.0%
Over 84	106	3.9%	41	4.9%	65	3.5%
Unknown	399	14.8%	143	17.2%	256	13.8%
Mean age	62.6		62.7		62.5	
Education						
Less than high school	584	21.7%	167	20.1%	417	22.4%
Completed high school	849	31.6%	272	32.7%	577	31.0%
Vocational training	129	4.8%	34	4.1%	95	5.1%
Attended college	387	14.4%	127	15.3%	260	14.0%
College graduate	389	14.5%	134	16.1%	255	13.7%
Graduate work	96	3.6%	30	3.6%	66	3.6%
Unknown	256	9.5%	67	8.1%	189	10.2%
*Employment						
Full-time	604	22.5%	174	20.9%	430	23.1%
Part-time	251	9.3%	95	11.4%	156	8.4%
Unemployed	600	22.3%	198	23.8%	402	21.6%
Retired	1029	38.3%	311	37.4%	718	38.6%
Other	151	5.6%	37	4.5%	114	6.1%
Unknown	55	2.0%	16	1.9%	39	2.1%
Average income						
Under \$5,000	399	14.8%	126	15.2%	273	14.7%
\$5,000-\$15,000	786	29.2%	247	29.7%	539	29.0%
\$15,001-\$30,000	600	22.3%	180	21.7%	420	22.6%
\$30,001-\$50,000	203	7.5%	65	7.8%	138	7.4%
Over \$50,000	72	2.7%	27	3.2%	45	2.4%
Unknown	630	23.4%	186	22.4%	444	23.9%
Driving Distance from Elder (in minutes)						
Lives in same household	2153	80.0%	669	80.5%	1484	79.8%
1 - 10	238	8.8%	79	9.5%	159	8.6%
11 - 30	155	5.8%	47	5.7%	108	5.8%
Over 30	40	1.5%	13	1.6%	27	1.5%
Other/Unknown	104	3.9%	23	2.8%	81	4.4%
*Length of caregiving before program entry (in months)						
0 - 6	386	14.3%	141	17.0%	245	13.2%
7 - 12	298	11.1%	102	12.3%	196	10.5%
13 - 24	427	15.9%	137	16.5%	290	15.6%
25 - 36	346	12.9%	105	12.6%	241	13.0%
37 - 72	539	20.0%	150	18.1%	389	20.9%
72 or more	473	17.6%	132	15.9%	341	18.3%
Unknown	221	8.2%	64	7.7%	157	8.4%
*Mean length of caregiving	42.5		39.4		43.8	

\* Difference between the brief users and the extended group significant at  $p \leq .05$

his or her current needs or expectations. From this perspective, an analysis of brief users should be an important part of any evaluation of respite services, because they may constitute a population of caregivers that is not being served adequately or equitably. The purpose of this analysis, then, was to examine the characteristics of brief users of respite services and, in particular, to identify the factors associated with brief use in order to determine whether there is something about the manner in which services are being offered that may disadvantage this group of potential users.

### **Previous Research**

At least two investigations have examined the phenomenon of brief use of respite services. A groundbreaking study by Cox (1997) used Andersen's (1968) behavioral model to identify factors potentially related to respite use. The behavioral model identifies three types of individual characteristics as the primary determinants of service use: predisposing, enabling, and need factors. The predisposing variables in the study by Cox (1997) included socio-demographic characteristics of the elder and caregiver, length of time and hours spent caregiving, and the caregiver's relationship to the elder. Enabling variables encompassed resources that might affect access to respite and included the caregiver's informal relationship with others who might provide expressive or instrumental support as well as the use of other formal services. Need on the part of the care recipient included ADL status, level of cognitive impairment, and behavior problems. Need on the part of the caregiver included anxiety, depression, burden, and the extent to which the caregiver felt that he or she had benefited from the caregiving role. The results indicated that caregivers who used respite services for a period of six months or less were more likely to be White than were persons using services for a longer period. No other differences were identified.

Two issues arise from the study by Cox (1997) that affect the interpretability of her findings. First, the study sample included both users of day care and in-home services. Although both services are intended to provide relief to caregivers, these services obviously differ from one another in important ways. As data from the ADDGS program will illustrate, day care and in-home respite also serve different populations of users. Failure to differentiate between these services may have obscured important differences in reasons for non-use. Second, Cox defined brief use as the use of respite for six months or less. In the career of a respite user, six

months is actually a substantial period of time. For example, the average length of use of respite among all clients in the ADDGS program is only ten months. It seems likely that the definition of brief use employed by Cox allowed for the inclusion of a large number of clients at late stages in the caregiving career. For example, over half of the brief users in the study by Cox said that the reason they stopped using respite was because they had placed their relative in a nursing home. An additional one-third reported stopping because of the death of the elder. In short, over 80% of the brief users could actually be characterized as conventional respite users; they simply represented caregivers who were in later stages of the caregiving career. This group of individuals is likely to be very different from persons who discontinue respite services, yet continue in their caregiving role.

In a more recent study, Zarit, Stephens, Townsend, Greene and Leitsch (1999) attempted to correct both of these limitations. First, they focused only on use of adult day care. Second, they restricted the definition of brief use to include individuals who used services for three months or less. This definition of brief use reduced the proportion of the sample that consisted of brief users sample who stopped service use because of institutionalization of the care recipient. Only 35% of the brief users in the study by Zarit and his colleagues terminated services due to placement in contrast to 50% of the sample in the study by Cox.

The analyses conducted by Zarit and his colleagues (1999) included potential covariates of brief respite use that were derived from the stress process model of caregiving (Pearlin, Mullin, Semple and Skaff, 1990). In this model, caregiving is viewed as a continuing process of stress and adaptation in which personal and social resources are used, as necessary, to contain the effects of primary stressors. Based on this model, covariates of extended use and, conversely, brief use, were hypothesized to include social resources (represented by socio-demographic characteristics), severity of patients' symptoms, and caregivers' appraisals of stressors, and their own levels of well-being. Using this approach, Zarit and his colleagues identified a number of correlates of brief use. Specifically, brief users had less formal education, were likely to be a spouse caregiver, more likely to be male, and have lower levels of depressive symptoms. In addition, care receivers tended to have higher ADL impairment and more behavior problems

A potentially serious limitation of both the studies by Cox and by Zarit et al. is the almost

exclusive focus on individual characteristics of either the caregiver or the elder, in their explanations for brief use. Respite is a service that is similar to other consumer-driven services in the sense that decisions to use the service almost certainly are influenced by characteristics of the service itself. For example, sustained service use is likely to be influenced by whether the respite is provided by a paid professional or a volunteer, the availability of a health component, the fee structure, and whether there is a limit to the amount of respite that can be used.

Program characteristics are likely to have differential appeal to caregivers, depending upon each caregiver's specific needs and circumstances. Although respite can take many forms, most respite programs are of two general types: adult day care (ADC) and in-home respite. ADC typically occurs in a group setting, is primarily custodial, does not provide intensive medical care, involves structured activities for relatively high functioning individuals, and affords little flexibility in scheduling. In contrast, in-home respite may have greater appeal to caregivers who care for patients with more serious health and behavioral impairments, and for those who need greater flexibility in scheduling. It seems likely that characteristics of respite programs will affect users differently, depending upon whether they are using ADC or in-home respite. For example, failure to provide skilled nursing care is likely to have a greater adverse effect on users of in-home respite who are caring for elders with greater physical impairment than it would on users of ADC.

### **Hypothesized Models of Respite Use**

A comprehensive model of brief respite use, then, should include both characteristics of the users and characteristics of the services. Moreover, the factors related to brief use are likely to vary depending upon the type of respite service under consideration, since different services, such as ADC and in-home respite, attract different populations of users. Consistent with this understanding, both individual and provider characteristics are explored as factors associated with brief use of respite services.

### ***Characteristics of the Individual***

Seven characteristics of the caregiver and elder that have been found to be related to brief use in previous research were identified for inclusion in these analyses: ethnicity, education, relationship to the patient, gender, employment status, ADL/IADL, and problem behaviors.

Both Cox (1997) and Zarit et al. (1999) reported that White caregivers were more likely to be brief users. Since minority status is typically associated with an under use of services (see Wolinsky et al., 1990), this relationship may seem counter intuitive. In the context of the ADDGS, however, such is not the case. Since the goal is to serve traditionally under served populations, particularly minority and rural caregivers, a special effort has been made to attract and retain minority caregivers.

Previous research has also found that lower education levels, being a spouse caregiver, and being a male caregiver are all to be associated with brief use of ADC (Zarit et al., 1999). Of these variables, only relationship status (i.e., spouse) affords a clear explanation for its effects. As Zarit and his colleagues note, spouses are likely to be reluctant to use respite on a continuous basis due to the socio-emotional aspects of their role. That is, they have stronger feelings of obligation and affection and suffer greater personal and social sanctions for turning the care for their spouse over to a formal provider. The role of education and gender are less clear, although males may be more likely to institutionalize their spouse than female caregivers.

Stressors or need factors such as the elder's need for ADL assistance and the extent of problem behaviors have also been shown to be related to brief use of ADC (Zarit et al., 1999), although logic would suggest that they have greater relevance to sustained use of ADC than to in-home respite. For example, increased need for ADL/IADL assistance frequently exceeds the capacity of many ADC programs, which may lack medical facilities or staff with medical training. Also, as ADL/IADL impairment increases, it also becomes more difficult for caregivers to get the client ready for the ADC program. Elders who exhibit problem behaviors may similarly tax the resources of the day care staff and may be perceived as being unlikely to benefit from programming. Consequently, these factors are likely to be associated with brief use of ADC, but not with in-home respite.

Evidence concerning the relationship between employment status of the caregiver and brief respite use is equivocal. On the one hand, it was found to be unrelated to brief use in the study by Cox (1997). On the other hand, it has been suggested to be an important covariate in understanding the manner in which the relationship of the caregiver to the elder is related to brief use of ADC (Zarit et al., 1999). Specifically, since adult children are more likely to be employed than spouses, respite use allows them to remain employed and still keep their parent

at home. From this perspective, employment status serves as a potentially important control variable in understanding generational differences in brief use.

### ***Characteristics of the Respite Program***

In addition to characteristics of the service users, a number of characteristics of the respite service were hypothesized to be related to brief use. These factors include: service capitation, fee structure, staffing patterns, availability of health or personal care, hours of operation or service availability, and type of service.

Many programs have policies that limit the amount of respite that can be used by any family. Depending upon the individual circumstances of the caregiver, when the amount of respite available is strictly limited, its attractiveness to caregivers may be diminished.

Cost was also hypothesized to affect brief use. Zarit and his colleagues (1999) found that non-subsidized respite was associated with brief use at the bivariate, but not the multivariate, level. Although a subsidy can be expected to lessen the impact of cost on brief use, a subsidy is unlikely to remove the total impact of service cost because of the variability in the manner in which a subsidy can be implemented. For example, some programs have a set fee structure or a percentage co-payment. Other programs use a sliding fee scale based on the caregiver's income or accept voluntary contributions. Clearly, even when subsidized, some programs can establish very restrictive fee structures. From this perspective, it seems reasonable to expect that fee structures will impact decisions about service use.

Staffing refers to whether the respite workers are paid professionals or volunteers. Professional caregivers are more likely to have specialized training and to be able to handle difficult cases involving the provision of routine medical care or dealing with problem behaviors. It was hypothesized that staffing would be more relevant for in-home respite programs than for ADC for two reasons. First, in general, in-home clients tend to be more impaired as indicated by greater ADL impairment or have more problem behaviors than do most clients of adult day care. Thus, when in-home respite workers are paid employees, caregivers will be less likely to be brief users. In contrast, since adult day care tends to serve clients with lower levels of impairment, whether the respite worker is a paid professional versus a volunteer is less likely to

matter. Additionally, an ADC setting affords the simultaneous presence of both paid and volunteer workers. In contrast, a volunteer may be the only worker present in an in-home setting.

A related characteristic of the respite service involves the provision of some health care services. A number of programs provide a health care component using trained professional personnel. The ability to receive health care services is likely to be most relevant to users of in-home respite who are likely to be caring for AD patients with higher levels of impairment. However, in some states Medicaid reimbursement is only available for persons using Adult Day Health services as opposed Social Day Health services. This reimbursement factor may also influence use patterns.

In the case of adult day care, whether the program is based on a group model as opposed to a traditional day care model is also likely to affect sustained use. Group day models tend to use volunteers and offer limited amounts of respite (e.g., one or two afternoons per week). When the needs of caregivers exceed the level of services offered by group day programs, caregivers are more likely to end up as brief users.

A similar circumstance occurs for in-home respite. Programs with greater flexibility will undoubtedly accommodate more potential users. Thus, when the hours during which services are offered are flexible, and can be adapted to meet the needs of clients, instances of brief use are likely to decline. Similarly, since in-home respite users are more likely to require personal care for their patients, whether the in-home program provides such care is likely to alter its utility to potential users. Specifically, when personal care is provided, the probability of brief use can be expected to decrease.

### **Description of Measures**

#### ***Demographic variables***

As noted earlier, demographic information was gathered at the time of client intake.

Demographic variables included in this analysis are ***ethnicity, relationship of the caregiver to***

*the care recipient, sex of the caregiver, and employment status.* For this analysis caregiver's employment status was categorized as full time employment, part time employment or not working.

### ***Measures of Primary Stressors***

Measures of the client's functional status and problem behavior were included as indicators of primary stressors. The client's functional status was measured with a 13-item composite measure of Activities of Daily Living (ADL) and Instrumental Activities of Daily living (IADL) that includes items from the Katz et al. (1963) ADL scale. Problem behaviors were measured with the 15-item inventory used by Pearlin and his colleagues (1990).

### ***Measures of Programmatic Characteristics***

Seven measures of programmatic characteristics were included in the analyses. Four of these measures were gathered for both day care and in-home programs. The measure of ***staffing patterns*** indicates the type of workers employed. This is a dichotomous variable indicating whether the program was staffed solely by paid staff or by a combination of paid and volunteer employees. The ***capitation of hours*** is the maximum number of hours that a program will provide to a single client in a year. For in-home providers the scale ranged from 50 to 1,920 hours annually. For day care providers, the scale ranged from 80 to 2,880 hours annually. The availability of services related to ***health care*** was measured with a dichotomous variable. Providers of respite services used four different types of fee structures. These ***fee structures*** included: co-payment, sliding fee scale, set fee scale, and voluntary contribution. Each of these fee structures was coded into a dichotomous variable.

The ***type of program*** classified the kind of Adult Day Care program was provided. Day Care Centers either operated on the Brookdale Group Day Care model which provides three to four hours of care once or twice a week or they operated for six or more hours four to five days a week. Some providers operated both types of services. Finally, a dichotomous variable, ***flexibility of operating hours***, was created to reflect whether the hours of operation were flexible and could be adapted to meet the needs of clients.

## **Data Analyses**

Two types of analyses were used to evaluate factors that were associated with brief use of respite services. First, the demographic and functional characteristics of caregivers and elders identified as brief users (i.e., service use duration of two months or less) were compared to those of persons identified as extended users (service use duration greater than two months). Second, logistic regression procedures were used to examine the relationship between brief use and client and provider characteristics. These regressions were conducted in a stepwise procedure. In the first step, only the set of socio-demographic variables were entered into the model. In the second step, the set of programmatic characteristics were entered to determine if they added significantly to the model.

## **Brief Users of Day Care**

### ***Comparison of Characteristics of Brief Users to Extended Users***

Brief day care users differed significantly from extended users on numerous characteristics including elder's race, geographic location, living arrangement, number in household, activities of daily living (ADL), problem behaviors, caregiver's relationship to elder, and caregiver's employment status. The characteristics of elders using day care for both the brief and extended user groups are reported in Table 2.3. Black/African-Americans were less prevalent in the brief user sample (24.8%) than in the extended sample (36.3%) as were Hispanics who comprised 10.5% of the brief users and 11.4% of the extended users. In contrast, the extended user sample included a lower proportion of Whites (47.3%) than did the brief user sample (58.9%). Brief users were more likely than elders in the extended user group to reside in rural areas (49.7% vs. 44.0%) and less likely to live urban locations (44.2% vs. 49.1%). A larger proportion of the brief user group than the extended sample lived with their spouse (41.4% vs. 35.8%) and a smaller number lived with their adult children (34.1% vs. 39.2%). Consistent with this pattern of living arrangement, brief users were also more likely than persons in the extended sample to live with only one other household member (47.3% to 41.9%). Finally there was a significant difference between the two samples in the mean scores for impairment of activities of daily living (ADL) and problem behaviors.

Characteristics of caregivers included in the day care sample are shown in Table 2.4. Spouses

were more prevalent as caregivers for the brief user group than for the extended group (37.0% vs. 30.4%) and adult children were less prevalent for the brief user group (46.7% vs. 50.7%). Consistent with this greater prevalence of spouse caregivers in brief user group, a greater proportion of brief users were married (70.3%) than was the case in the extended group (66.1%) and a slightly higher proportion of the extended group was widowed (6.2% vs. 5.0%). Finally, caregivers of brief users were less likely than those in the extended group to be employed full-time (24.8% vs. 31.4%), and more likely to be retired (33.9% vs. 26.9%).

### **Predictors of Brief Use of Day Care**

As shown in Table 2.7 the multivariate logistic regression analysis, the set of socio-demographic variables added vastly to the predictive efficacy of the model of brief use of ADC (*Chi-square* = 50.79, *df*=10). The regression coefficient for each variable is also shown in Table 2.7 along with its standard error. In reasonably large samples, such as the present, the test of whether the regression coefficient departs significantly from zero approximates a *z*-test. Thus, coefficients approximately twice the size of the standard error or greater are considered statistically significant. The exact probability level of each *b*/*SE* ratio under the null hypothesis of no effect (i.e., the coefficient = 0) is also given. The values for *Exp(B)* in the right-hand column are antilogged logit coefficients that indicate the relative odds of being classified as a brief user versus a longer user. These values are shown only for the coefficients that attained statistical significance. Values of *Exp(B)* greater than 1 indicate that higher scores on the predictor variable increase the probability of being in the brief user group; values less than 1 indicate a decreased likelihood.

Three variables from the set of individual characteristics had significant unique effects on the probability of being a brief user. Consistent with the earlier findings by Cox (1997), ethnicity emerged as a significant predictor of brief use of ADC. Both Black/African-Americans and Latino/Hispanics were less likely than Whites to be brief users. Also, as hypothesized, when the number of problem behaviors increased, so did the likelihood of being a brief user of ADC.

**TABLE 2.7 MODEL OF BRIEF-TERM USE OF DAY CARE**

	Demographics Only (N = 2193)			Full Model (N = 2193)		
	b/SE	Sig.	Exp(B)	b/SE	Sig.	Exp(B)
Black/African-American	-.60/.12	.00	.55	-.56/.14	.00	.57
Hispanic/Latino	-.28/.17	.11		-.36/.19	.06	
Caregiver Education	-.03/.04	.34		-.04/.04	.26	
Child Caregiver	.08/.16	.60		.05/.16	.74	
Spousal Caregiver	.18/.18	.31		.15/.18	.42	
Elder's Sex	.01/.13	.93		.04/.13	.77	
Composite ADL/IADL	-.01/.01	.31		-.01/.01	.29	
Problem Behaviors	.03/.01	.00	1.03	.03/.01	.00	1.03
Fulltime Employed	-.21/.13	.11		-.20/.13	.14	
Parttime Employed	-.19/.18	.29		-.19/.18	.29	
Staffing				.03/.07	.73	
Capitation of Hours				-.02/.01	.03	.98
Health Care Component				.29/.13	.02	1.33
Copayment Required				.56/.44	.20	
Sliding Fee Scale				.29/.17	.09	
Set Fee Scale				-.22/.21	.28	
Constant	-.85/.33	.01	.43	-.99/.37	.01	.37
Chi-Square Change	50.79	.00		12.51	.05	
Degrees of Freedom	10			6		

When the set of program characteristics were added to the model of brief use of ADC, there was a significant increase in the predictive efficacy of the model (*Chi-square* = 12.51, *df*= 6). Two programmatic variables emerged with significant unique effects: capitation of service hours and the presence of a health care component. When the amount of respite care that a

caregiver could use was strictly limited, the probability that the caregiver would become a brief user increased. Surprisingly, when there was a health care component to the ADC, the probability of brief use increased as well.<sup>1</sup>

### **Brief Users of In-Home Respite**

#### ***Comparison of Characteristics of Brief Users to Extended Users***

Characteristics of elders and caregivers included in the in-home sample are shown in Tables 2.5 and 2.6. Notably, elder brief in-home users differed significantly from the extended group on three variables: race, gender, and ADL measure. White elders were more likely to be in the brief user group (64.1% to 60%) while Black/African-Americans were more likely to be in the extended user group (26.6% to 32.7%). The proportion of brief users who were male (36.8%) was slightly higher than that of the extended sample (32.8%). Female elders were more likely to be in the extended group (65.4% to 61.6%) and the difference was statistically significant. Additionally, elders in the brief user group had significantly higher functioning ADL levels than those in the extended group. Caregivers in the brief user group also varied significantly from those in the extended group only on length of time caregiving before enrolling in the demonstration program. Caregivers in the brief user group averaged 39.4 months of prior caregiving, while caregivers in the extended user group had provided care an average of 43.8 months.

Table 2.8 shows the multivariate logistic regression analysis of brief use of in-home respite on the sets of predictors. The set of socio-demographic variables did not add significantly to the predictive efficacy of the model of brief use of in-home respite (*Chi-square* = 17.75, *df* = 10). However, the race variable for Blacks did obtain significance indicating that Blacks were less likely to be brief users of in-home health service. Furthermore, when the set of variables reflecting program characteristics were added to the model, the variables Black and Hispanic both became statistically significant indicating a lower probability of brief use for minority groups.

**TABLE 2.8 MODEL OF BRIEF-TERM USE OF IN-HOME RESPITE**

	Demographics Only (N = 2690)			Full Model (N = 2690)		
	<u>b/SE</u>	<u>Sig.</u>	<u>Exp(B)</u>	<u>b/SE</u>	<u>Sig.</u>	<u>Exp(B)</u>
Black/African-American	-.23/.11	.04	.79	-.24/.13	.06	
Hispanic/Latino	-.05/.22	.82		-.79/.27	.00	.45
Caregiver Education	.03/.03	.42		.03/.03	.43	
Child Caregiver	.15/.16	.35		.12/.16	.46	
Spousal Caregiver	.02/.18	.91		.01/.18	.96	
Elder's Sex	-.19/.11	.10		-.22/.12	.06	
Composite ADL/IADL	-.01/.01	.28		-.01/.01	.45	
Problem Behaviors	.01/.01	.14		.01/.01	.26	
Fulltime Employed	-.10/.14	.48		-.04/.14	.80	
Parttime Employed	.26/.16	.11		.32/.17	.05	1.38
Staffing				-.34/.05	.00	.72
Capitation of Hours				.01/.01	.42	
Health Care Component				-.66/.16	.00	.52
Copayment Required				.34/.15	.02	1.41
Sliding Fee Scale				.18/.12	.15	
Set Fee Scale				-.58/.20	.00	.56
Constant	-.54/.33	.10		.5/.40	.06	
Chi-Square Change	17.75	.06		70.59	.00	
Degrees of Freedom	10			6		

When the set of program characteristics were added to the model of brief use of in-home services, there was a significant increase in the predictive efficacy of the model ( $Chi-square = 70.59, df = 6$ ). Four programmatic variables emerged with significant unique effects: type of staffing, the presence of a health care component, required co-pay, and a set fee scale. When an all paid staff was used (i.e., no volunteers), brief use was less likely. Similarly, if the in-home program contained a health care component, the probability of brief use decreased. Finally, relative to voluntary fee structures, co-pay structures were associated with brief use while a set-fee structure was associated with extended use.

## **Discussion**

### ***Brief Use of Day Care***

The findings from the logistic analyses reveal a profile that suggests that day care use is most desired for clients with limited impairment. First, the positive relationship between brief user status and problem behaviors suggests that day care is most appropriate for dementia clients who do not exhibit a high degree of problem behaviors. This likely reflects the limited capacity of day care providers to care for persons with problem behaviors. At the same time, the positive relationship between the availability of health care services and brief use is a bit perplexing. It may be that persons with limited functional and mental impairment best suited to day care use. Even with the availability of health care services, it may be difficult for caregivers to fully utilize day care when the functional status of the elder is too limited. This conclusion is consistent with anecdotal reports that caregivers often find the difficulty of getting the client ready for day care too high of a price to pay for the limited relief that they will gain.

The findings also indicate that ethnicity matters--at least in the context of these demonstration data. Black/African-Americans are less likely to be brief term users of day care. The same pattern holds for Hispanic users, although the effect was less consistent. Stated conversely, Black/African-Americans and Hispanics are more likely to continue using day care after initial use. This pattern may reflect the success of the ADDGS demonstration to promote programs that more effectively serve these traditionally under-served populations.

### ***Brief Use of In-Home Respite***

The relationships observed between the individual covariates and brief respite use of in-home care is intuitively understandable if in-home care is viewed as the preference for the clients who are most impaired. For example, if the respite program employs paid workers, who tend to be better trained and more reliable than volunteers, caregivers are less likely to be brief-term users. For caregivers needing regular, scheduled relief, this pattern makes sense. In turn, if the in-home program offers health care services, clients are more likely to extend their use of services. That is, they are more likely to find the service useable for a more extended period of time.

Initially, one would logically expect caregivers to prefer programs with voluntary fees rather than mandatory set fee structure. However, voluntary fees alone do not offset programs that fail to meet the perceived needs of caregivers. In these data, programs with voluntary fees are significantly correlated with agencies that do not offer assistance with household tasks or personal care. That is, brief user status is a product of insufficient formal care, not voluntary fee structures. Additionally, set fee structures provide prospective users clear guidelines as to cost that allow them to make informed decisions and financial plans accordingly.

Brief users of in-home respite appear to have greater need for professional health and household assistance. In these data, the status of brief user is primarily a product of agency programming, as opposed to a product of elder and caregiver characteristics. The picture that emerges from these findings is one in which program characteristics shape patterns of in-home use, or more precisely, discontinued use. This finding is of particular interest because it provides clues to ways that programs might be altered to encourage continued use of services. Programs that offer assistance with household tasks and personal care, particularly those staffed by paid professionals, appear to be most useful to these caregivers. Thus, brief term users of in-home respite may constitute a sub-population of caregivers with unmet needs unlike those of continuous users.

## **PATTERNS OF RESPITE USE OVER TIME**

### **Reduction of Study Population for Data Analyses**

Data for 1148 day care clients and 1432 in-home clients were analyzed to identify profiles of extend respite use. To ensure an accurate and complete representation of each individual's trajectory of service use, data were included only for those clients who had completed their participation in the ADDGS program. For example, a client who is in the first month of service use could either stop (and become classified as a brief user) or continue use for an indeterminate amount of time. Since it is impossible to know which pattern will occur in advance, accurate classification is impossible. Similarly, including individuals who are at some unknown point in their spell of use would likely result in under estimating their total use for one or more of the definitions of "use" employed in this study. Therefore, analyses were limited to clients for whom complete data were available.

Although attempts were made to collect current care status information on every family in the sample, this information was not available for 669 cases (15.4%). Current care status was available for 3759 clients (84.6%). The majority of these (1202 elders, 27.5%) had been institutionalized, 823 elders (18.8%) had died, and 81 elders (4.1%) had moved. Additionally, 180 elders (4.1%) had discontinued services, 9 elders (0.2%) had become inappropriate for services (i.e., inappropriate behavior in day care settings), 593 elders (13.6%) had begun using services outside of the demonstration, and 712 elders (16.3%) were still using ADDGS supported services.

Hence, of the 2193 clients initially identified as users of day care services, 640 were designated as brief users, 1148 were included in the longitudinal analysis, and 405 were excluded from the analyses either because they continued to use services or their current care status was unknown. Similarly, of the 2690 clients initially identified as users of in-home services, 1432 were included in the longitudinal analysis, 831 were identified as brief users and 427 were excluded from the analyses because they continued to use services or their current care status was unknown.

With only minor exceptions, the characteristics of day care and in-home clients excluded from the longitudinal sample largely mirrored those included in the sample. A detailed comparison of

characteristics of two longitudinal samples with those of clients excluded from the analyses is provided in Appendix 2E. Generally, for both types of services, Black/African-Americans comprised a slightly larger proportion of the cases excluded from the analysis (i.e. 42% vs. 34% for day care and 40% vs. 30% for in-home). In contrast Hispanic/Latinos comprised a larger proportion of the sample included in the longitudinal analysis for day care respite than in the excluded group (6.7% to 13.1% respectively). In addition, adult children were more prevalent in the longitudinal sample of day care users than in the group excluded from the analysis (52% vs. 46%). Also, for the analysis of in-home respite use, persons from urban locations were less prevalent in the longitudinal sample than in the excluded group (40% vs. 32%).

### **Characteristics of Day Care Users and In-Home Users**

Demographic data for the 2395 client families who used services for more than two months are reported in Tables 2.9 and 2.10. Characteristics are reported separately for users of day care services and in-home services. Past research has suggested that users of day care services have different profiles than users of in-home services (Montgomery and Kosloski, 2000). This is based, in part, on the belief that the relationship of the caregiver to the care receiver and the magnitude of care required will impact the respite use patterns. In general, adult children comprise a larger portion of day care users, while spouse caregivers are more likely to use in-home respite services. Additionally, spouse caregivers usually wait until much later in the caregiving career to accept services, whereas adult children usually seek formal assistance when help with personal care is needed. Thus, since these user groups are known to be different types of users with different needs at different times, it is important to separate day care users and in-home users from dual service users and to analyze each individually.

### ***Elder Characteristics***

The demographic characteristics of elders, shown in Table 2.9 by service type, are similar to the national profiles of persons with dementia. The majority of the longitudinal sample was White (55.8%), while Black/African-Americans and Hispanics/Latinos made up 32.3% and 8.5% of the sample, respectively. When viewing users of the different services separately, there was a significant relationship between race of the elder and type of service used. In this sample, Whites (63.8%) were more likely to use in-home respite services than were Black/African-American (30.7%) and Hispanic/Latino (3.4%) elders. Hispanics/Latinos elders (15%) made up a somewhat larger proportion of day care users than of in-home users as did Black/African-

**TABLE 2.9 ELDER CHARACTERISTICS BY SERVICE TYPE : LONGITUDINAL SAMPLE**

	<b>All Services</b>		<b>Day Care Only</b>		<b>In-Home Only</b>		<b>Both Services</b>	
	<b>2395</b>	<b>100%</b>	<b>852</b>	<b>35.6%</b>	<b>1143</b>	<b>47.7%</b>	<b>400</b>	<b>16.7%</b>
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
<b>*Race</b>								
White	1337	55.8%	391	45.9%	729	63.8%	217	54.3%
Black/African-American	773	32.3%	293	34.4%	351	30.7%	129	32.3%
Hispanic/Latino	203	8.5%	128	15.0%	39	3.4%	36	9.0%
Other	67	2.8%	34	3.8%	17	1.5%	16	4.0%
Unknown	15	0.6%	6	0.7%	7	0.6%	2	0.5%
<b>*Geographic Location</b>								
Urban	955	39.9%	453	53.2%	351	30.7%	151	37.8%
Rural	1281	53.5%	342	40.1%	712	62.3%	227	56.8%
Unknown	159	6.6%	57	6.7%	80	7.0%	22	5.5%
<b>*Average Income</b>								
Under \$5,000	330	13.8%	132	15.5%	149	13.0%	49	12.3%
\$5,000 - \$15,000	1378	57.5%	487	57.2%	650	56.9%	241	60.3%
\$15,001 - \$30,000	402	16.8%	118	13.8%	220	19.2%	64	16.0%
\$30,001 - \$50,000	61	2.5%	21	2.5%	32	2.8%	8	2.0%
Over \$50,000	17	0.7%	7	0.8%	8	0.7%	2	0.5%
Unknown	207	8.6%	87	10.2%	84	7.3%	36	9.0%
<b>Gender</b>								
Male	797	33.3%	289	33.9%	383	33.5%	125	31.3%
Female	1548	64.6%	544	63.8%	738	64.6%	266	66.5%
Unknown	50	2.1%	19.0	2.2%	22	1.9%	9	2.3%
<b>*Marital Status</b>								
Single	124	5.2%	49	5.8%	55	4.8%	20	5.0%
Married	1027	42.9%	305	35.8%	564	49.3%	158	39.5%
Widowed	1096	45.8%	434	50.9%	466	40.8%	196	49.0%
Other	116	4.8%	53	6.2%	46	4.0%	17	4.3%
Unknown	32	1.3%	11	1.3%	12	1.0%	9	2.3%
<b>*Living Arrangement</b>								
Live Alone	342	14.3%	99	11.6%	179	15.7%	64	16.0%
Live with Spouse	1001	41.8%	293	34.4%	556	48.6%	152	38.0%
Live with Children	817	34.1%	350	41.1%	319	27.9%	148	37.0%
Other	214	8.9%	96	11.3%	83	7.3%	35	8.8%
Unknown	21	0.9%	14	1.6%	6	0.5%	1	0.3%
<b>*Total Number in Household</b>								
Live Alone	342	14.3%	99	11.6%	179	15.7%	64	16.0%
Elder + 1 other	1166	48.7%	350	41.1%	632	55.3%	184	46.0%
Elder + 2 others	459	19.2%	179	21.0%	203	17.8%	77	19.3%
Elder + 3 or more	404	16.9%	208	24.4%	123	10.8%	73	18.3%
Other/Unknown	24	1.0%	16	1.9%	6	0.5%	2	0.5%
<b>Number of Services Used Prior to Entry</b>								
0	822	34.3%	299	35.1%	382	33.4%	141	35.3%
1 - 2	1247	52.1%	437	51.3%	609	53.3%	201	50.3%
3 or more	326	13.6%	116	13.6%	152	13.3%	58	14.5%

\* Difference between day care and in-home groups significant at p <= .05

\* Difference between both service and single service user groups significant at p <= .05

**TABLE 2.9. ELDER CHARACTERISTICS BY SERVICE TYPE: LONGITUDINAL SAMPLE..continued**

	<b>All Services</b>		<b>Day Care Only</b>		<b>In-Home Only</b>		<b>Both Services</b>	
	<b>2395</b>	<b>100%</b>	<b>852</b>	<b>35.6%</b>	<b>1143</b>	<b>47.7%</b>	<b>400</b>	<b>16.7%</b>
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
<b>*Alzheimer's Disease</b>								
Suspected	421	17.6%	152	17.8%	203	17.8%	66	16.5%
Diagnosed	1726	72.1%	585	68.7%	848	74.2%	293	73.3%
Other	242	10.1%	112	13.1%	90	7.9%	40	10.0%
Unknown	6	0.3%	3	0.4%	2	0.2%	1	0.3%
<b>Functional Level</b>								
*#Mean ADL (0 - 10)	3.9		3.0		4.7		3.4	
*#Mean IADL (0 - 16)	12.7		12.1		13.2		12.3	
<b>Problem Behavior</b>								
#Mean Score (0 - 45)	12.7		12.3		12.7		13.4	
<b>*Mean age</b>	79.3		78.3		80.0		79.7	

\* Difference between day care and in-home groups significant at p <= .05

# Difference between both service and single service user groups significant at p <= .05

**TABLE 2.10 CAREGIVER CHARACTERISTICS BY SERVICE TYPE: LONGITUDINAL SAMPLE**

	<b>All Services</b>		<b>Day Care Only</b>		<b>In-Home Only</b>		<b>Both Services</b>	
	<b>2395</b>	<b>100%</b>	<b>852</b>	<b>35.6%</b>	<b>1143</b>	<b>47.7%</b>	<b>400</b>	<b>16.7%</b>
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
<b>*Gender</b>								
Male	624	26.1%	198	23.2%	322	28.2%	104	26.0%
Female	1703	71.1%	622	73.0%	800	70.0%	281	70.3%
Unknown	68	2.8%	32	3.8%	21	1.8%	15	3.8%
<b>*Relationship to elder</b>								
Spouse	872	36.4%	255	29.9%	481	42.1%	136	34.0%
Adult child / child-in-law	1128	47.1%	447	52.5%	477	41.7%	204	51.0%
Other relative	242	10.1%	80	9.4%	127	11.1%	35	8.8%
Friend	59	2.5%	23	2.7%	24	2.1%	12	3.0%
Professional care manager	45	1.9%	31	3.6%	7	0.6%	7	1.8%
Self	7	0.3%	2	0.2%	3	0.3%	2	0.5%
Unknown	42	1.8%	14	1.6%	24	2.1%	4	1.0%
<b>*Marital Status</b>								
Single/Divorced	504	21.0%	193	22.7%	221	19.3%	90	22.5%
Married	1649	68.9%	566	66.4%	814	71.2%	269	67.3%
Widowed	162	6.8%	54	6.3%	78	6.8%	30	7.5%
Unknown	80	3.3%	39	4.6%	30	2.6%	11	2.8%

\* Difference between day care and in-home groups significant at p <= .05

# Difference between both service and single service user groups significant at p <= .05

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**TABLE 2.10 CAREGIVER CHARACTERISTICS BY SERVICE TYPE: LONGITUDINAL SAMPLE --Continued**

	All Services		Day Care Only		In-Home Only		Both Services	
	2395	100%	852	35.6%	1143	47.7%	400	16.7%
	N	%	N	%	N	%	N	%
Age (in years)								
44 or less	295	12.3%	117	13.7%	116	10.1%	62	15.5%
45 - 54	383	16.0%	144	16.9%	168	14.7%	71	17.8%
55 - 64	392	16.4%	136	16.0%	179	15.7%	77	19.3%
65 - 74	430	18.0%	132	15.5%	235	20.6%	63	15.8%
75 - 84	384	16.0%	92	10.8%	226	19.8%	66	16.5%
Over 84	75	3.1%	14	1.6%	51	4.5%	10	2.5%
Unknown	436	18.2%	217	25.5%	168	14.7%	51	12.8%
*#Mean age	61.3		58.7		63.6		59.9	
*#Education								
Less than high school	507	21.2%	172	20.2%	257	22.5%	78	19.5%
Completed high school	698	29.1%	228	26.8%	364	31.8%	106	26.5%
Vocational training	121	5.1%	44	5.2%	52	4.5%	25	6.3%
Attended college	385	16.1%	159	18.7%	152	13.3%	74	18.5%
College graduate	379	15.8%	159	18.7%	149	13.0%	71	17.8%
Graduate work	89	3.7%	30	3.5%	42	3.7%	17	4.3%
Unknown	216	9.0%	60	7.0%	127	11.1%	29	7.3%
*#Employment								
Full-time	654	27.3%	296	34.7%	258	22.6%	100	25.0%
Part-time	212	8.9%	81	9.5%	92	8.0%	39	9.8%
Unemployed	505	21.1%	173	20.3%	228	19.9%	104	26.0%
Retired	829	34.6%	234	27.5%	471	41.2%	124	31.0%
Other	135	9.0%	37	4.3%	72	6.3%	26	6.5%
Unknown	60	2.5%	31	3.6%	22	1.9%	7	1.8%
*#Average income								
Under \$5,000	312	13.0%	94	11.0%	159	13.9%	59	14.8%
\$5,000-\$15,000	649	27.1%	199	23.4%	335	29.3%	115	28.8%
\$15,001-\$30,000	544	22.7%	186	21.8%	264	23.1%	94	23.5%
\$30,001-\$50,000	191	8.0%	87	10.2%	74	6.5%	30	7.5%
Over \$50,000	67	2.8%	31	3.6%	23	2.0%	13	3.3%
Unknown	632	26.4%	255	29.9%	288	25.2%	89	22.3%
Driving Distance from Elder (mins.)								
Lives in same household	1931	80.6%	699	82.0%	903	79.0%	329	82.3%
1 - 10	211	8.8%	71	8.3%	104	9.1%	36	9.0%
11 - 30	133	5.6%	41	4.8%	73	6.4%	19	4.8%
Over 30	28	1.2%	13	1.5%	13	1.1%	2	0.5%
Other/Unknown	92	3.8%	28	3.3%	50	4.4%	14	3.5%
Length of caregiving before program entry (months)								
0 - 6	349	14.6%	129	15.1%	145	12.7%	75	18.8%
7 - 12	258	10.8%	90	10.6%	126	11.0%	42	10.5%
13 - 24	375	15.7%	120	14.1%	180	15.7%	75	18.8%
25 - 36	316	13.2%	115	13.5%	140	12.2%	61	15.3%
37 - 72	490	20.5%	176	20.7%	254	22.2%	60	15.0%
72 or more	387	16.2%	114	13.4%	217	19.0%	56	14.0%
Unknown	220	9.2%	108	12.7%	81	7.1%	31	7.8%
*#Mean length of caregivi	41.5		39.1		44.5		37.6	

\* Difference between day care and in-home groups significant at  $p \leq .05$  # Difference between both service and single service user groups significant at  $p \leq .05$

American elders (34.4%). In contrast, White elders (45.9%) used day care services in smaller numbers than they did in-home services.

Differences between users of the different types of service in geographic location were also significant. The majority of the total sample was located in rural areas (53.5%) with just under 40% living in urban areas. Approximately 7% of the sample did not specify whether they lived in an urban or rural community. In-home service users were similarly distributed with 62.3% in rural areas and 30.7% in urban centers. In contrast, the majority (53.2%) of the elders using only day care lived in urban areas and just over 40% lived in rural towns.

The majority (71.3%) of all user groups had incomes under \$15,000 per year. This remained true for users of each service type; 73% of day care users and 70% of in-home users had annual incomes under \$15,000. Nearly two-thirds of elders were female. This is consistent with national demographic statistics indicating greater longevity of females, and thus a greater likelihood of requiring assistance with care. A larger proportion of day care clients were widowed (50.9%) and fewer were married (35.8%) than in the sample of in-home respite users (40.8% widowed; 49.3% married).

Living arrangement also varied significantly by service type. The majority of elders either lived with their spouse (41.8%) or their children (34.1%); only 14.3% lived by themselves. A lower proportion of elders using day care resided with a spouse (34.4%) than with an adult child (41.1%). Elders using in-home services were more likely to live with their spouse (48.6%); 27.9% lived with their children, and 15.7% lived alone. Although the largest proportion of elders resided in a two person household with their caregiver, a small proportion lived alone, and 36.1% lived in households of three or more persons. A higher proportion of elders who used in-home services resided in two person households than was true for users of day care (41.1%) or dual users (46%). Conversely a higher proportion of day care users than of in-home respite users (45.4% versus 28.6%) resided in homes with two or more other persons.

Prior to using the demonstration services, just over half the elders in all categories had used one or two other community-based services. The majority of elders (72.1%) had received a

formal diagnosis of Alzheimer's disease prior to enrolling in the demonstration. Fewer elders who used day care (68.7%) had a formal diagnosis than did elders who used in-home respite services (74.2%). This pattern is consistent with the usual timing of in-home respite use within the context of the caregiving career. Caregivers tend to use in-home respite in later stages of the disease process and thus, are more likely to have sought out, or had time to receive, a formal diagnosis. Additionally, 13.1% of elders using day care and 7.9% of elders using in-home respite had a diagnosis other than Alzheimer's disease.

There were also statistically significant differences between the groups in measures of functional status. In-home respite clients had higher average scores on both ADL (4.7) and IADL (13.2) measures than did day care clients, whose scores were 3.0 and 12.1, respectively. Similarly, in-home respite users, on average, had higher scores on the 15-item measure of problem behaviors than did users of day care (12.7 versus 12.3). The lower levels of functioning and greater number of problem behaviors displayed by in-home respite users suggest that clients utilize this service in later stages of dementia. The average age of the elders differed by service type as well, with users of day care being slightly younger (78.3 years) than users of in-home respite (80 years).

### ***Caregiver Characteristics***

Demographic characteristics of caregivers, as shown in Table 2.10, mirrored those of the elders. Females comprised approximately 71.1% of the caregiver population as a whole, with few differences observed between users of day care (73%) and in-home (70%) services. Adult children were the largest segment of caregivers in each group, making up 47.1% of the sample. This percentage varied by service type, with adult children comprising 52.5% of the caregivers who used day care and only 41.7% of those utilizing in-home respite. As expected, the pattern was reversed for spousal caregivers, who made up 42.1% of in-home respite users, and only 29.9% of day care users.

Differences between the two groups in the distribution of marital status and average age are linked to the differences observed in the prevalence of spouse and child caregivers. A higher proportion of the caregivers using in-home services were married (71.2%), as opposed to 66.4% of those involved in day care. With an average age of 58.7 years, caregivers of the day care

group were significantly younger than their peers who used in-home respite (63.6 years). This again reflects the relationship-based differences between users of day care and in-home respite.

Education, employment, and income levels varied for users of the different services. Subtle group differences can be observed in caregivers' levels of educational attainment. In general terms, the educational level of the sample was low, with more than 50.3% having only a high school diploma or less. However, nearly half of day care users had completed vocational training or more schooling (46.1%), while this was true for only 34.5% of caregivers receiving in-home respite. This pattern was also consistent for the caregiver's employment status. The full sample included 654 full-time workers (27.3%) and 829 retirees (34.6%). For in-home respite users, 22.6% of caregivers were working full-time and 41.2% were retired. In contrast, a higher frequency of day care users worked full-time (34.7%) than were retired (27.5%). While 62.8% of the sample as a whole earned less than \$30,000 annually, users of in-home respite are more concentrated at the low end than are day care users. This segment of the income spectrum encompasses 66.3% of persons receiving in-home respite, and 56.2% of those using day care. These disparities likely reflect the differences in age between the caregivers of in-home users and caregivers of day care users. The younger caregivers are generally more likely to provide care while remaining employed, thus resulting in higher household incomes.

Finally, patterns of caregiving are somewhat different between groups. Caregivers' physical proximity to elders was constant throughout the sample; the most common situation was the elder residing in the same household as the caregiver (80.6%). Despite this similarity, caregivers who utilized in-home respite waited longer before seeking assistance from the demonstration. On average, they provided care for 44.5 months before beginning service, while the average for persons who chose day care was 39.1 months.

### **Characteristics of Users of Both Services**

Primary attention in this report has been given to the distinctive profiles of day care and in-home respite users. By design, each form of respite provides a unique type of relief from caregiving and subsequently attracts different types of clients. However, there are a number of families

who utilize both day care and in-home respite. The longitudinal sample included 400 (16.7%) families who used both types of service. Characteristics of this group (Both Services), shown in Table 2.9 and 2.10, are provided separately from those clients who utilized day care exclusively or in-home exclusively. In identifying users of both services, no minimum amount of either service was required for families to be recorded as dual users of respite. That is, a family could theoretically use only two hours of day care but more than four hundred hours of in-home respite over the course of their participation in this demonstration and still be recorded as a dual user.

Overall, the characteristics of users of both services closely resembled users of day care and in-home clients. However, a small number of significant distinctions were observed. For the elders, these distinctions included differences in the level of ADL, IADL, and problem behavior. For the caregivers, differences were observed in mean age and educational level.

Elders using both services had ADL and IADL scores that were significantly higher (3.4 ADL and 12.3 IADL) than those of day care users (3.0 ADL and 12.1 IADL) and lower in comparison to in-home users (4.7 ADL and 13.2 IADL). This is consistent with findings from past research that indicates a higher disability status for in-home elders than for day care elders. It is not surprising then to find clients who utilize both services having functional levels lower than those of day care users but above users of in-home services. In contrast, problem behavior measures were higher for elders using both services (13.4) than for those using either day care or for in-home (12.3 and 12.7 respectively). This may suggest that families, who must deal with difficult behaviors, seek out additional sources of support.

Caregivers using both services were generally older (59.9 years) than day care users (58.7 years), but younger than in-home users (63.6 years). Again, considering past research indicating that day care is typically used at earlier stages in the caregiving career than in-home services, this finding is consistent with expectations. Additionally, the educational status of caregivers utilizing both services was significantly higher than those using only in-home respite and slightly lower than those who used day care. Forty-seven percent of dual users had attended some form of post secondary education, 17.8% of which had college degrees.

## **Variables and their Measurement**

### ***Defining and Measuring Respite Use***

Although most previous studies have quantified the amount of service use in terms of total hours of respite used, this summary value does not capture the many ways that families may differ in their use of services. Families may vary in (1) the number of hours that is used on each occasion, (2) the duration of time (e.g. number of months) over which a family actually uses services, (3) the continuity of use within that duration period, and (4) the total number of hours of respite that is used. It is not only plausible that families will vary in their patterns of use as conceptualized and measured in these different ways, but it is also likely that a different set of factors may account for the variation in the different measures of use. Therefore, to fully describe patterns of respite use and capture differences among families in their patterns of use, it is important to conceptualize and measure use in several different ways.

For this study, respite use was conceptualized and measured in five ways.

The ***intensity*** of respite was defined as the number of hours used in each month.

The ***duration*** of respite use was defined as the number of months between the client's first occasion of use and the last occasion of use.

The ***continuity*** of respite use was measured as the ratio of number of months in which a family actually used the respite services relative to the number of months for which the family was eligible to use services

The ***total hours*** of respite used by a client is equal to the sum of all hours used over the eligibility period. (The ***eligibility period*** was defined as the period between enrollment in the demonstration project and departure from the project for any reason.)

Note that ***intensity*** of respite use is a time dependent variable that is measured monthly and can be analyzed with longitudinal statistical techniques. In contrast the other three measures of respite use are summary measures intended to capture variations in patterns of respite use that do not lend themselves to longitudinal analyses.

### ***Independent Variables***

Both client characteristics and provider characteristics were examined as plausible predictors of respite utilization profiles.

**Characteristics of Elders and Caregivers.** A wide range of characteristics of the elder care recipient and the family member providing care were investigated as possible predictors of respite use patterns. The set of individual characteristics included as plausible predictors was selected based on findings from previous studies of caregiving behaviors and service utilization (see Montgomery and Kosloski, 2000 for a detailed review.) Demographic characteristics of the caregiver included in the analyses are: *relationship of the caregiver to the elder* (i.e. spouse, child, other family member) *ethnicity*, *gender*, *income* and *employment status*. The elder characteristics included in the analyses are: *gender*, *age*, *health* and *functional status*, *living arrangement* (i.e., alone or with caregiver), and *geographic residence* (urban versus rural settings).

**Provider Characteristics.** Five types of provider characteristics were considered as factors likely to influence patterns of respite use. They included: (1) caps or limitations on amount of service available to each and a measure of the level of flexibility a provider used in enforcing these caps; (2) hours and/or days of operation; (3) type of staffing (voluntary versus paid); (4) type of service provided (social, companionship, personal care services, or a combination of both levels of care); and (5) fee structure (i.e., set fee, sliding scale, voluntary, or co-pay).

### **Approach to Statistical Analysis**

A general linear mixed model was used to examine the pattern of client use of the two respite services (adult day care and in-home) over time and to identify the client and provider characteristics that might affect these patterns of use. The mixed model is an appropriate model to use when observations on the dependent variables are nested or clustered such that the assumption of independence of observations is tenuous. In the case of the data analyzed in this study, there is nesting of data both within persons (the monthly repeated measures of the client's service use) and within organizations (the clients nested within service providers). The two levels of nesting in the data make them especially complicated to analyze. We were interested in: (1) determining whether clients' patterns of respite use differ among providers, and (2) identifying client and provider characteristics that might affect patterns of usage. As in any regression analysis, the variance in a model may be explained by a variety of covariates. In the linear mixed model, the between-subjects variance in the level or in the rate may be reduced by the inclusion of selected covariates. In this study, we explored a number of covariates representing characteristics of the elder and caregiver as well as characteristics of providers.

Our analytic approach was to examine these issues for each type of respite service in three steps. First, the patterns of client respite use as captured by each of the four measures (i.e., intensity, continuity, duration, total hours) were examined for each type of service. In the case of intensity, which was measured monthly, these patterns were modeled over time. Second, we examined the effects of client and provider characteristics on each of three summary measures. Finally we modeled the pattern of client use over time as measured by intensity over time and examined together all factors affecting intensity of use. A detailed discussion of the modeling and mathematical foundations for the analysis of the longitudinal data is presented in Appendix 2F.

## FINDINGS

### Average Amount of Respite Use

The mean scores for each measure of respite use are shown by type of service in Table 2.11 along with the average *eligibility period* for clients. For both types of services the average period of eligibility for clients was slightly more than 19 months. The mean *duration* of service use was 14.9 months for families using in-home services and 16.2 months for day care. On average, clients used respite services just over 70% of that period as indicated by the scores for *continuity* of use. In contrast to the similarity of duration observed for the two types of services, there was a significant difference between the two types of services in the average *intensity* (number of hours used) of use by clients. Day care clients used an average of 50 hours of respite per month, which was twice the amount used by in-home clients. This difference in the number of hours used per month was reflected in the large disparity observed between the two types of services in the *total number of hours* used by clients. The average number of total hours of respite used by day care clients was 817 hours as opposed to 283 hours for in-home clients.

Although these general descriptions of the patterns of respite use provide baseline information for policy makers and providers, more valuable information is obtained when differences among caregivers in patterns of respite use are examined carefully. In particular, it is useful to identify client and provider characteristics that are associated with these differences and to examine variations in intensity of use over time.

Even though multi-level analyses were conducted for all of the summary measures of respite use, separate analyses for **total hours** of use are not reported here because the findings related to total number of hours of use are fully captured by the longitudinal analyses of intensity of use.

**TABLE 2.11 MEASURES OF USE BY SERVICE TYPE**

	Day Care N = 1148		In-Home Respite N = 1431	
	Mean	Std.Dev.	Mean	Std.Dev.
<b>*Period of Eligibility</b> (months)	19.3	13.2	19.1	13.6
<b>Average Intensity</b> (hours of use per month)	50.3	37.1	24.6	17.6
<b>Duration of Use</b> (months)	16.2	12.98	14.9	12.95
<b>Continuity of Use</b>	0.72	0.26	0.71	0.26
<b>Total Hours of Use</b>	817.2	1170.9	282.6	345.5

\*Not included as a dependent variable

### **Patterns of Client Use of Day Care**

#### ***Duration of Day Care Use***

The results of the multi-level analysis for duration of day care use are shown in Table 2.12. These findings reveal several patterns. First, the variance components for random effects reported in the bottom panel of the table indicate that there is some variation among providers in the mean level of client duration. However, the majority [ $146.22/(146.22+10.63)=93\%$ ] of the observed variance in duration of respite use stems from differences among individuals (146.22 versus 10.63).

The data reported in the upper half of Table 2.12 identify the factors that influence duration. Note that all of the factors found to be related to duration of respite use were characteristics of the caregiver or the elder. None of the provider characteristics were shown to be factors influencing the duration of service use. The client characteristics that are related to respite use

**TABLE 2.12 DAY CARE: DURATION OF USE**

<u>Fixed Effects</u>	<u>Effect Prob.</u>	<u>Coefficient</u>	<u>Std. Error</u>	<u>t Ratio</u>
<b>Intercept</b>		20.435	1.832	11.15
<b>PERSON VARIABLES</b>				
<b>Race</b>	.0028			
Black/African-Amer.		4.275	1.175	3.64
Hispanic/Latino		-.356	2.115	-.17
Other Race		.4189	2.750	.15
White		0		
<b>Employment</b>	.0091			
Full-time		2.417	.818	2.95
Part-time		-.084	1.244	-.07
Unemployed		0		
<b>Used Both Services</b>				
Yes	.0001	-3.736	.909	-4.11
No		0		
<b>IADL Score</b>	.0001	-.497	.116	-4.27
<u>Random Effects</u>		<u>Variance Comp.</u>	<u>z-Value</u>	<u>Prob. Of z</u>
<b>LEVEL ONE</b>				
<b>Individual Variation</b>		146.22	22.84	.0001
<b>LEVEL TWO (Client within Provider)</b>				
<b>Provider Initial Status</b>		10.63	2.36	.0091

are the elder's race and level of IADL impairment, the employment status of the caregiver, and whether or not the family used both types of respite care. The coefficient for the intercept indicates that the average duration of day care use was 20.4 months for persons in the referent group<sup>2</sup>. The average of 20.4 months is obtained by holding constant the effects of all the other predictor variables in the model by fixing their levels at some particular, arbitrary value. In the present case, these arbitrary values are the values for the comparison or omitted groups in the analysis. For this analysis, the intercept represents the average duration for an individual who is White, unemployed, who cares for an elder with no IADL impairment, and who used respite only in the form of day care. The coefficients for the different ethnic groups indicate the increase or decrease in number of hours associated with each group when compared to the referent group. The average duration of respite use for Hispanic/Latino caregivers was only slightly less than that of Whites (-.36 of a month); the duration for persons included in the other ethnic groups was slightly longer (.42 months) than for Whites. The duration of respite use for clients who used both in-home and day care respite was shorter by almost 4 months (-3.7). The

duration of service used decreased by a half of month for every full point increase in IADL impairment. Overall, this analysis indicates that Black/African-American caregivers, who are employed full time and are caring for persons with minimal IADL impairment, tend to use services for the longest periods of time.

### **Continuity**

Findings related to the continuity of day care use are reported in Table 2.13. Again, the variance components shown in the lower panel of the table indicated that the majority [ $19.84/(19.84 + 2.24) = 89\%$ ] of variation in continuity of use was due to variation among individuals, although there was a small, statistically significant amount of variation between providers in the average continuity of service use among clients. Also, as was true for duration, variation in the amount of continuity of use was primarily influenced by individual characteristics rather than provider characteristics. Only the fee structure of the provider had a significant influence on the continuity of service use among clients.

**TABLE 2.13 DAY CARE: CONTINUITY OF USE**

<u>Fixed Effects</u>	<u>Effect Prob.</u>	<u>Coefficient</u>	<u>Std. Error</u>	<u>t Ratio</u>
Intercept		.665	.056	11.98
<b>PERSON VARIABLES</b>				
Relationship	.0049			
Child		.037	.019	1.96
Other Relative		-.039	.027	-1.46
Spouse		0		
Prior Services	.0284			
None		-.071	.028	-2.60
1 - 2		-.060	.025	-2.36
3 or more		0		
ADL Score	.0474	-.007	.003	-1.99
<b>PROVIDER VARIABLES</b>				
Fee Structure	.0083			
Percentage Copay		-.375	.124	-3.03
Sliding Scale		.036	.050	.73
Voluntary Contribution		.006	.057	.10
Set Fees		0		
<u>Random Effects</u>		<u>Variance Comp.</u>	<u>z-Value</u>	<u>Prob. Of z</u>
<b>LEVEL ONE</b>				
Individual Variation		.057	19.84	.0001
<b>LEVEL TWO (Client within Provider)</b>				
Provider Initial Status		.007	2.44	.0074

The intercept coefficient of .665 indicates that persons with characteristics of the reference category on each predictor variable used day care two thirds of the time for which they were eligible<sup>2</sup>. For this analysis, families in the reference group were those who (1) had a spouse caring for an elder with no ADL impairments, (2) had used three or more services prior to enrollment, (3) used both types of respite after enrollment, and (4) were enrolled in programs with set fees. Coefficients for the covariates in the model indicate that the level of continuity, which could range between 0 and 1, is slightly higher (.037) among families with an adult child caregiver and slightly shorter (-.039) for families with a more distant relative providing care. Families who used no support services or only 1 or 2 support services prior to entering the demonstration used services for a slightly smaller proportion of the eligibility period (-.071 and -.060 respectively). An increase of one point on the ADL impairment score is associated with a .05 increase in continuity. Finally, the requirement of co-payment for use of a program was associated with a large and significant decrease in continuity. In fact, the reduction in continuity of -.375 associated with co-pay would reduce the continuity rate by 50% (.665 -.375).

### ***Intensity of Day Care Use***

Initially, analyses were conducted for three different measures of intensity of services: the average number of hours used per month, the total number of respite hours used over the eligibility period, and the monthly use of respite over the duration of use. Findings for the three different measures were almost identical and therefore only the longitudinal analyses of monthly use are reported here.<sup>3</sup>

**Variation in Day Care Use Over time and Across Providers.** The use of day care respite by clients over time was analyzed using a three level model, as repeated measures were available on this measure of respite use for each family. As before, all of the potential predictor variables were examined (i.e., client characteristics, caregiver characteristics, provider characteristics, and time). For clarity and parsimony, only the significant predictors are included in the final model. Results of this analysis are shown Table 2.14. The variance components for the random effects shown in the bottom panel reveal several important facts about variation in day care use. The variance component for level 1, which is labeled “temporal variation” indicates that the number of hours of respite used by each client varies significantly over the period that respite is used. The level 2 variance component labeled “client initial status” indicates that there is also significant variation among individuals served by the same provider in the number of hours of day care at the time of initial use. The second variance component

**TABLE 2.14 DAY CARE: INTENSITY OF USE**

<b>Fixed Effects</b>	<b>Effect Prob.</b>	<b>Coefficient</b>	<b>Std. Error</b>	<b>t Ratio</b>
<b>Intercept</b>		23.768	7.033	3.38
<b>TIME</b>				
Linear	.8056	.084	.140	.60
Quadratic	.0001	-.013	.002	-6.58
Linear * Duration	.0004	.016	.005	3.52
Linear * Race	.0022			
Black/African-Amer.		-.428	.132	-3.25
Hispanic/Latino		-.147	.191	-.77
Other Race		.380	.292	1.30
White		0		
<b>PERSON VARIABLES</b>				
Race	.1050			
Black/African-Amer.		3.460	2.832	1.22
Hispanic/Latino		12.761	5.530	2.31
Other Race		5.678	7.373	.77
White		0		
Relationship	.0079			
Child		4.967	1.644	3.02
Other Relationship		4.814	2.266	2.12
Spouse		0		
Used Both Services				
Yes	.0003	6.609	1.835	3.60
No		0		
Prior Services	.0636			
None		-2.759	2.364	-1.17
1-2		-4.860	2.182	-2.23
3 or more		0		
Caregiver Gender				
Female	.0017	-5.429	1.672	-3.14
Male		0		
Duration of Use	.0035	.173	.059	2.92
IADL Score	.0383	.468	.226	2.07
<b>PROVIDER VARIABLES</b>				
Day Care	.0366	-13.483	6.310	-2.14
Cap	.0039	.012	.004	3.00
<b>Random Effects</b>		<b>Variance Comp.</b>	<b>z-Value</b>	<b>Prob. Of z</b>
<b>LEVEL ONE</b>				
Temporal Variation		275.70	71.61	.0001
<b>LEVEL TWO (Client within Provider)</b>				
Client Initial Status		418.46	18.81	.0001
Client Rate of Use		.996	9.73	.0001
<b>LEVEL THREE</b>				
Provider Initial Status		356.24	4.61	.0001
Provider Rate of Use		.018	.60	.2758

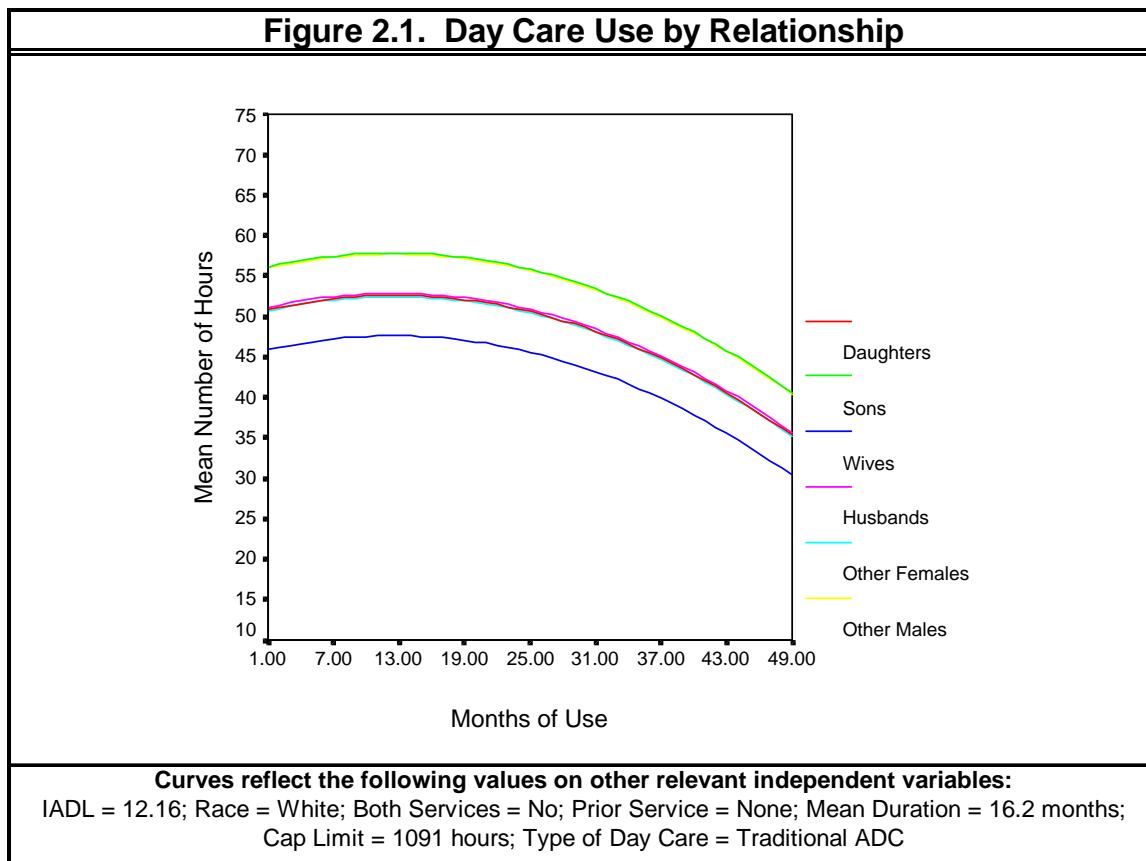
reported under level 2, which is termed “client rate of use”, indicates that there is significant variation between clients in their patterns of increase or decrease in hours of service used over time. The level-3 variance component for “provider initial status” indicates that there is significant variance across providers in the initial level of day care use by clients. The second variance component reported for level 3, which is labeled “provider rate of use”, is very small and non-significant. This indicates that the patterns of change in respite use are not significantly different across providers.

The coefficients reported in the top panel of Table 2.14 provide information about the initial level of day care use, as well as information about the change in this use over time. The linear and quadratic coefficients reported under the heading of “Time” describe the pattern of monthly change in use of day care. As indicated by the non-significance of the linear component, the pattern of change is not linear. The significance of the relatively small negative coefficient (-.013) for the quadratic component indicates that the change in use over time is best described as an “inverted U” which increases slightly to about the tenth month and then decreases more steeply in the later months. This pattern is depicted in Figure 2.1 for six types of caregiver relationships. The findings reported in Table 2.14 also indicate that two client characteristics moderate the pattern of change over time. The coefficients for the multiplicative terms (Linear\*Duration and Linear\*Race) representing the interaction of the linear component with duration and with race are both statistically significant. Since both duration and race also influence the initial level of day care use, it is most helpful to describe the impact of each variable on the trajectory of use with the discussion in the next section of the impact of race and duration on the level of initial use.

**Impact of Client Characteristics on Intensity of Day Care Use.** The coefficient reported for the intercept term in the top panel of Table 2.14 indicates persons with characteristics representing the reference group on each of the predictor variables will use 23.77 hours of respite in the initial month of respite use. Members of the reference group for this analysis were White, male, spouse caregivers who had used three or more services previously, and were now using only one type of respite service.

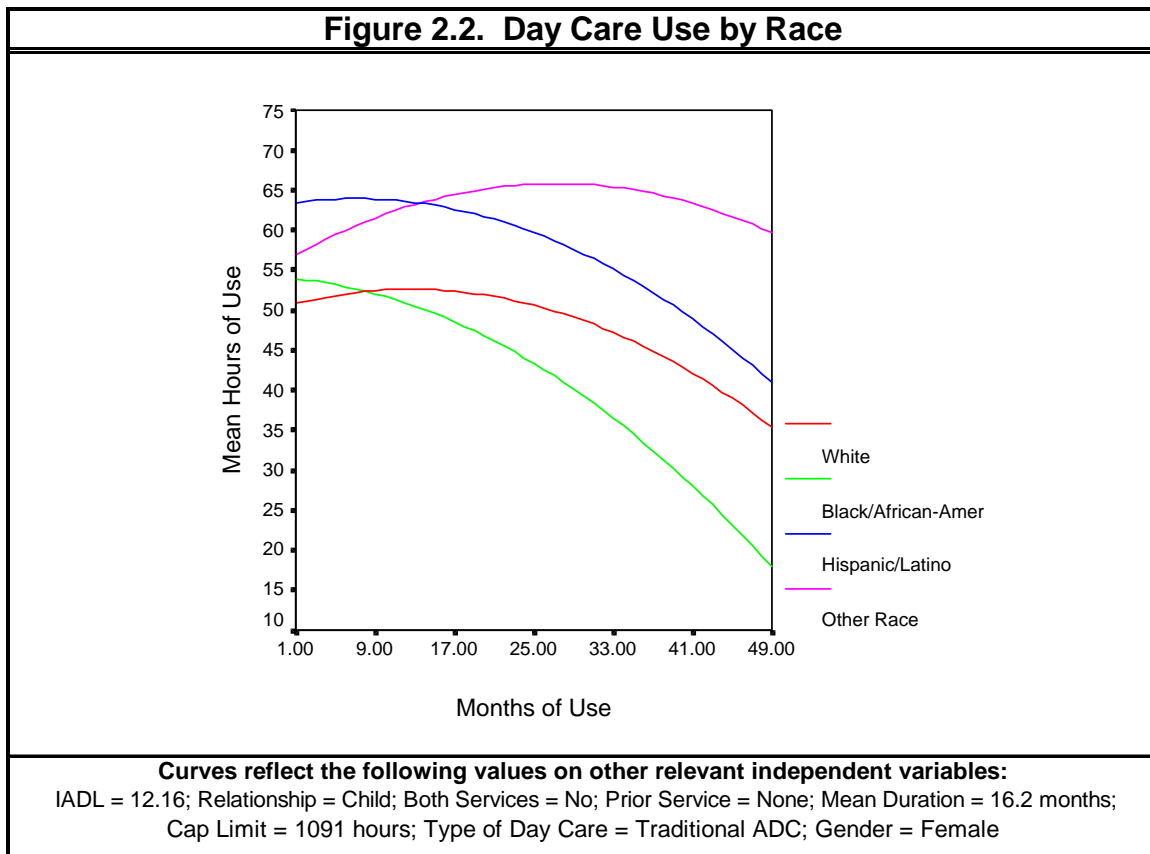
Several client characteristics were related to an increase or decrease in this quantity. They

include: relationship of the caregiver to the elder, race, caregiver sex, elder's level of impairment in IADLs, the number of support services used prior to enrollment in the demonstration, the use of in-home respite and the duration of day care use. Caregivers who were children and other more distant relatives used almost 5 more hours of day care per month than did spouses; female caregivers used 5.4 hours less of day care than did males. Notably there is almost no difference between children and other relatives in the number of hours of day care. The sex of the caregiver also influences the number of day care hours used at the time families begin using services.



The combined effects of these two key caregiver characteristics on the patterns of service use, net of the other factors, are shown in Figure 2.1. The points at which each curve shown in Figure 2.1 intersects the y-axis (Mean Number of Hours) depict this difference in initial level of use. Clearly, the lowest initial use of day care occurs when wives are caring for husbands. It is interesting to note that the level of day care use is almost equal for families with a husband, daughter, or other female caring for the elder. The pattern for sons is most similar to the pattern for "other male relatives".

Referring back to Table 2.14, the average number of hours of respite use in the first month of service was 12.8 hours more for Hispanics/Latinos than for Whites. Although, on average, Blacks/African-Americans used 3.5 more hours of day care than did Whites and persons from other ethnic groups used 5.7 more hours than Whites, differences for these groups were not statistically significant. The differences among racial/ethnic groups in the initial level of day care use did not remain constant over time because race also differentially affected the patterns of change in respite use over time. These differences are illustrated in Figure 2.2. The steeper curve shown for Blacks/African-Americans indicates that the decrease in hours of day care used in later months by Blacks/African-Americans (green line) is much greater than that observed for any of the other ethnic groups. The curve for Hispanics/Latinos (blue line) is only slightly steeper than the curve for Whites, while the curve for caregivers of other ethnic backgrounds is flatter. Thus, over time Black/African-American clients steadily decrease their use, while caregivers of other ethnic groups tend to maintain levels of use consistent with the amount of their initial use.



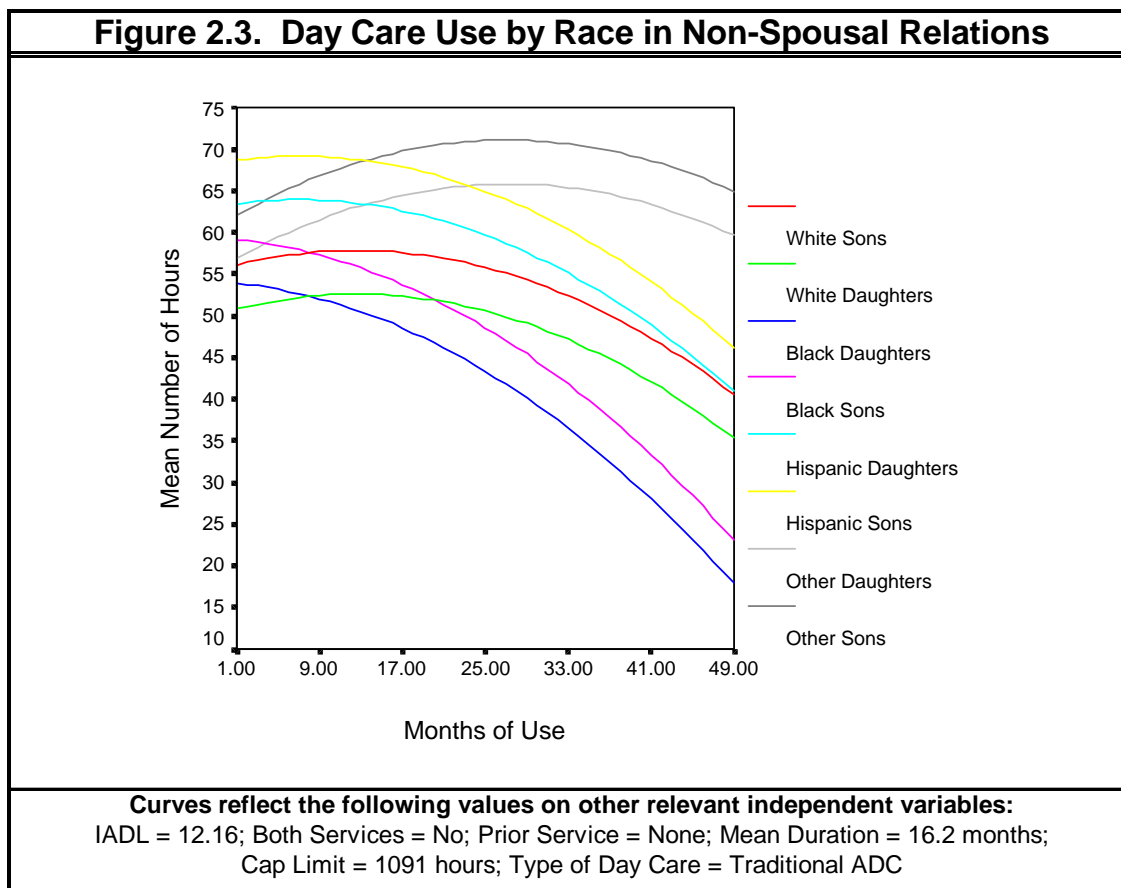
The differences in level of change over time that are associated with ethnicity lead to interesting changes in the relative ranking among ethnic groups in intensity of use. As shown in Figure 2.2, White families used the lowest number of hours of respite when they initially began using day

care; Hispanic/Latino caregivers used the highest number of hours at the time of initial use. Additionally, the number of hours of day care used initially by Black/African-American families and families from other backgrounds ranged between Whites and Hispanics/Latinos. Over time, this pattern changes. The number of hours of day care use by Black/African-American families drops below the level for Whites at about the 10-month point. By the end of 49-month period shown in Figure 2.2, the intensity of respite use among Black/African-American families is substantially lower than that of all of the other groups. In contrast, after about 16 months of use, caregivers designated as “other ethnic groups” have higher levels of services use than all other groups. They tend to maintain this higher level through their duration of use. The patterns of change for Hispanics/Latinos and Whites are very similar, resulting in greater intensity of day care use for Hispanics/Latinos throughout the 49 months charted in the graph.

The combined impact of type of caregiver relationship, gender and race are illustrated in Figures 2.3, 2.4, and 2.5. Several differences in the patterns of use for the different groups are worthy of note. First, the curves depicted in Figure 2.3 for sons and daughters indicate the relative influence of race and gender on patterns of care changes over time. At the time of initial service use, Hispanic caregivers use more day care than do caregivers from any of the other ethnic groups regardless of their gender. In contrast the gender of the caregiver is more important than race for Black/African-American and White caregivers. Both Black/African-American and White elders who are cared for by a son use more services at the time of initial day care use. This pattern changes over time with race becoming more important for predicting service use among long term users (at about 20 months) than is gender. Also, the trajectory of change for elders from the category “other ethnic groups” increases for a longer period of time than is true for any of the other groups. Consequently, the number of hours of day care used by elders in this group surpasses that of Hispanics after approximately 25 months of use. Among all racial groups, elders cared for by sons use more services than do those assisted by a daughter.

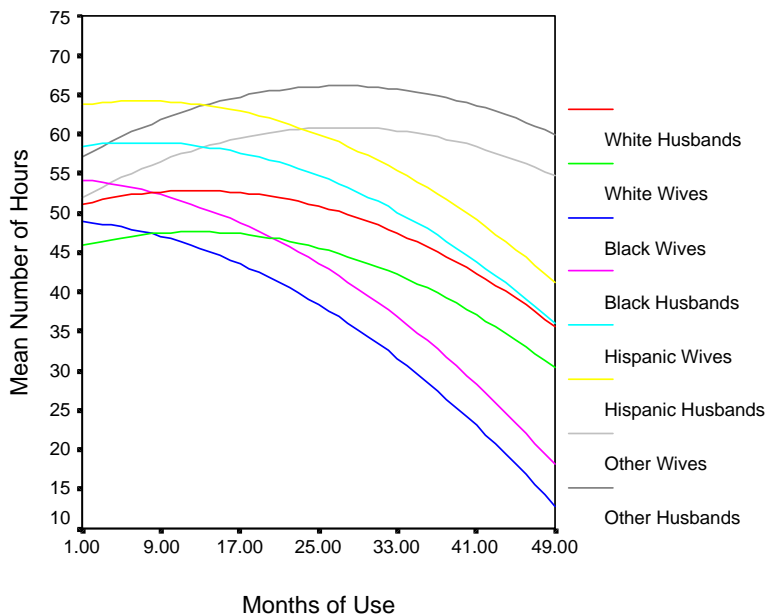
A similar pattern of differences in day care use is depicted in Figure 2.4 for husbands and wives. At the point of initial use, Hispanic elders used more hours of care than did any of the other ethnic group regardless of the gender of the spouse caregiver. For the other three ethnic groups, the influence of race and gender are more equal. While wives in each ethnic group used fewer services than did husbands of the same ethnic group, wives in the “other ethnicity” group used more services than either Black/African-American or White husbands. Among long

term users of day care, race dominates over gender as a predictor of service use. After approximately 25 months of service use, there is a clear ranking of service use by race with husbands in each group using more than wives.



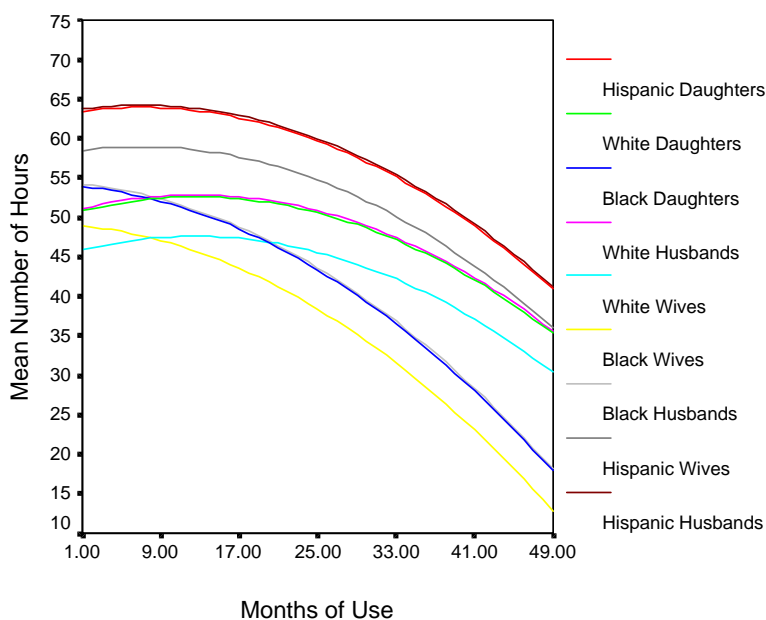
The curves depicted in Figure 2.5 are particularly interesting because they illustrate the similarity among elders cared for by husbands and daughters. For every ethnic group, husbands and daughters used more services than did wives and their patterns of use over time continued to be almost identical. Throughout the entire duration of use, Hispanic/Latino elders used more day care than any other group. The pattern for Whites and Blacks/African-Americans is slightly different. At the time of initial use Blacks/African-Americans of all relationships use more hours of service than do Whites. Over time this pattern is reversed. After 9 months of service use, Black/African-American elders used fewer hours of day care than did their White counterparts with similar role relationships (i.e. husband, wife, daughter). After 19 months of service use, Black/African-American elders used fewer hours of service than all of the other ethnic groups regardless of the caregivers' relationship to the elder.

**Figure 2.4. Day Care Use by Race in Spousal Relations**



**Curves reflect the following values on other relevant independent variables:**  
IADL = 12.16; Both Services = No; Prior Service = None; Mean Duration = 16.2 months;  
Cap Limit = 1091 hours; Type of Day Care = Traditional ADC

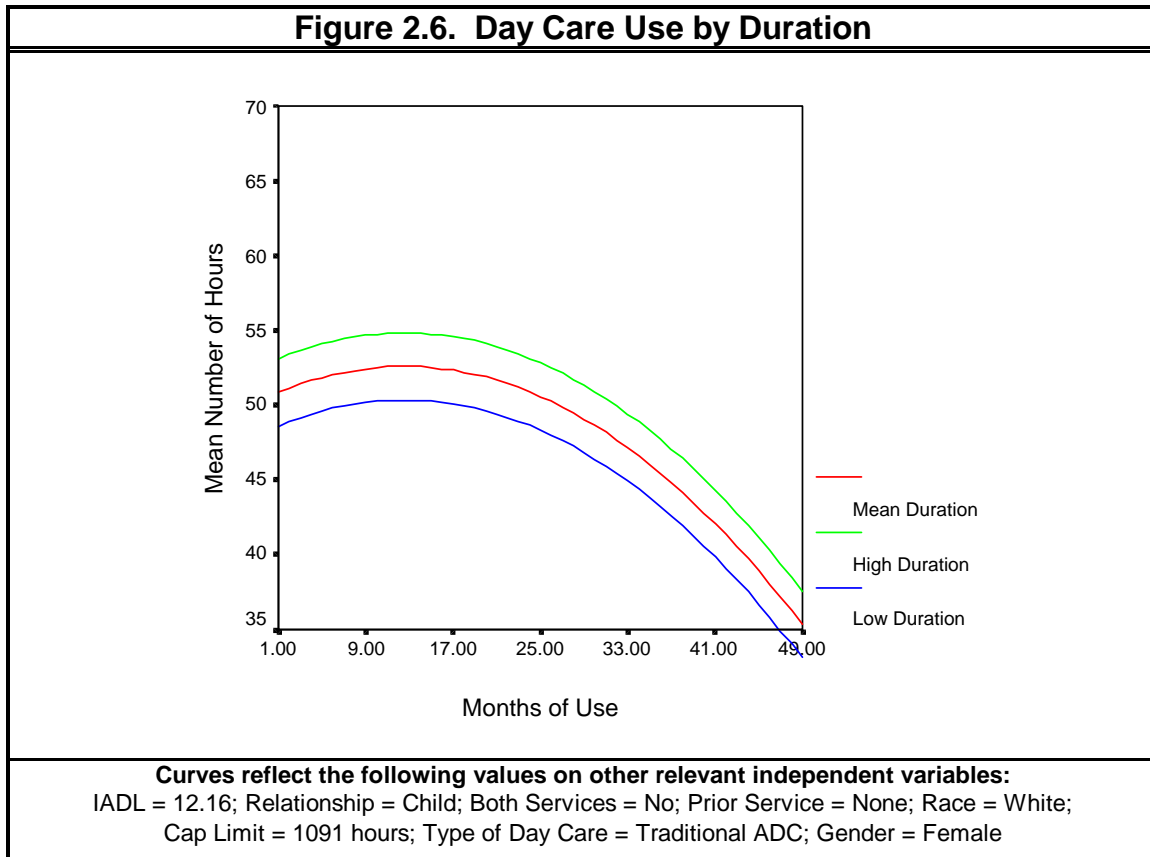
**Figure 2.5. Day Care Use by Race in Spouses and Children**



**Curves reflect the following values on other relevant independent variables:**  
IADL = 12.16; Both Services = No; Prior Service = None; Mean Duration = 16.2 months;  
Cap Limit = 1091 hours; Type of Day Care = Traditional ADC

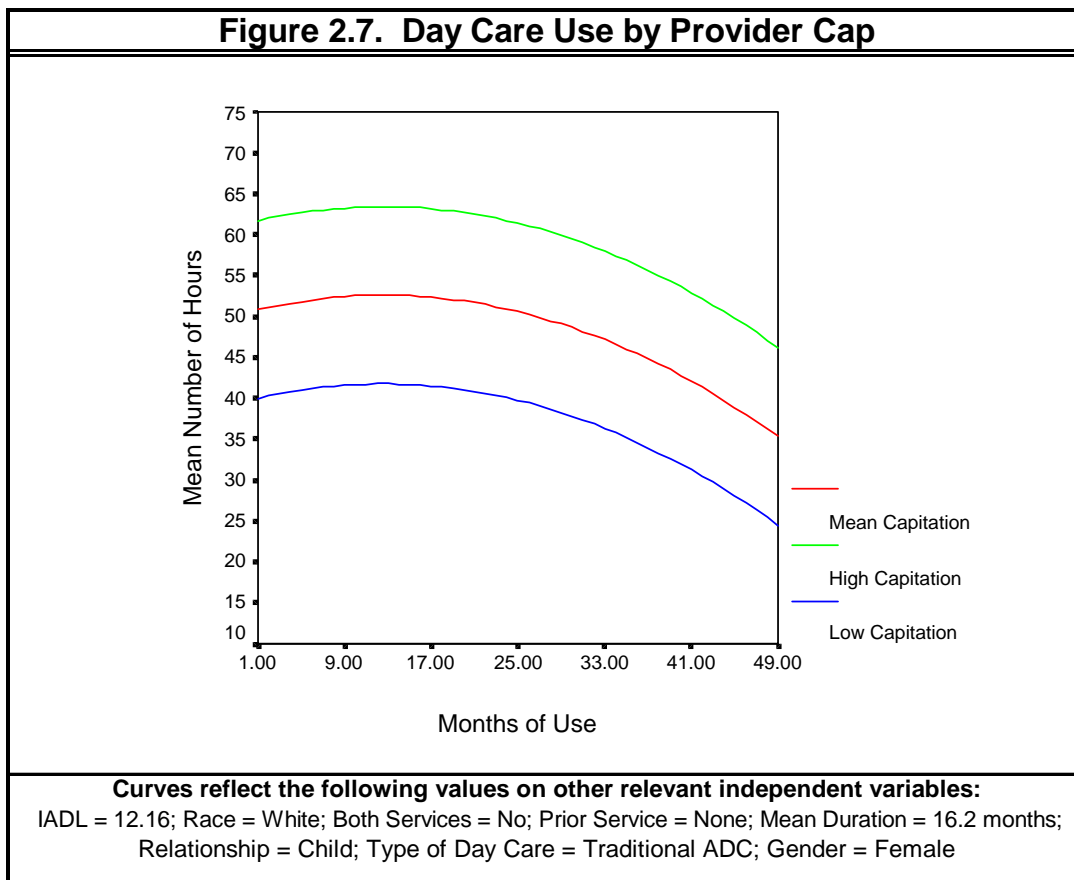
The data reported in Table 2.14 detail the impact of four additional client characteristics on the initial level of service use. For each point of increase in the measure of IADL impairment the number of hours of day care used increased by about one half-hour per month. Clients who used only day care services used 6.6 more hours of service (6.61) than did clients who used both types of respite care. Clients who had previously used no support services used 2.8 hours less of day care (-2.75) than those who had used three or more services prior to enrolling in the demonstration. Persons who had used one or two support services prior to enrollment in the program used almost five fewer hours of day care (-4.9).

Finally, in Table 2.14, the number of hours of day care used in the first month was greater by 0.17 for each additional month that a family ultimately used day care. Duration is the only characteristic, other than race, that changes the shape of the curve. However, the impact of duration on the rate of use was very minimal as shown in Figure 2.6. Essentially the amount of



day care use remained constant over the first 12 months. After that point, however, there was a tendency for all families to use similar amounts of service regardless of the duration of their use. That is, persons who ultimately went on to use services for a full 49 months (green line) tended to reduce the number of hours they used by a greater amount than did those families who used services for shorter periods. As a consequence, the curves depicting levels of use converge over time.

**Impact of Provider Characteristics on Intensity of Use** Two characteristics of the providers were associated with the intensity of day care use. Families who used group day care used 13.5 fewer hours at the time of initial use than did families enrolled in traditional day care programs. Also, the number of hours of day care used increased by .012 for each hour that was added to the maximum limit or cap that was placed on services by the provider. This difference related to agency caps is depicted in Figure 2.7. The center line in red represents the pattern



for families served by providers who have a limitation of 455 hours which is the mean level among the providers. This mean value represents the mathematical average of all provider caps. The other two lines represent the levels that are one standard deviation above and one standard deviation below this mean level. This range, represented by the standard deviation, captures the use patterns of 68% of the sample.

### **Patterns of In-home Respite Use**

#### ***Duration of In-home Use***

The findings from the multi-level analysis of duration of in-home service use are reported in Table 2.15. The variance components for random effects reported in the bottom panels reveal a pattern similar to that observed for duration of day care use. Ninety-two percent of the variance ( $150.1/(150.1+13.6)$ ) in the duration of in-home use stems from differences among individuals (where the variance component for individuals = 150.10 versus 13.56 for providers).

**TABLE 2.15 IN-HOME RESPITE: DURATION OF USE**

<u>Fixed Effects</u>	<u>Effect Prob.</u>	<u>Coefficient</u>	<u>Std. Error</u>	<u>t Ratio</u>
Intercept		19.639	1.626	12.08
<b>PERSON VARIABLES</b>				
Race	.0107			
Black/African-Amer.		3.017	.987	3.06
Hispanic/Latino		4.139	2.374	1.74
Other Race		-.490	3.002	-.16
White		0		
Used Both Services				
Yes	.0001	-3.757	.896	-4.19
No		0		
Elder's Age	.0001	-.177	.042	-4.19
<hr/>				
<u>Random Effects</u>		<u>Variance Comp.</u>	<u>z-Value</u>	<u>Prob. Of z</u>
<b>LEVEL ONE</b>				
Individual Variation		150.10	25.97	.0001
<b>LEVEL TWO (Client within Provider)</b>				
Provider Initial Status		13.557	4.805	.0024

The data reported in the top panel of Table 2.15 identify the factors that influence duration. Consistent with the findings for day care use, all of the factors found to be related to duration of in-home respite use were characteristics of the caregiver or the elder. None of the provider characteristics were shown to be factors influencing the duration of service use. The client characteristics that are related to in-home respite use are the elder's race and age and whether or not the family used both types of respite care. The coefficient for the intercept indicates that the average duration of day care use was 19.6 months for members of the referent group who are families with a White elder, aged 51 years who was using only in-home respite. The average duration of in-home respite use for Hispanic caregivers was 4.1 months longer. On average, Black/African-American elders used in-home services for 3 months longer than did Whites. Caregivers of other ethnic backgrounds did not vary significantly from Whites in the duration of use. The use of day care in combination with in-home respite reduced the average duration of in-home services by 3.8 months (-3.75). The use of in-home services was higher by about 5 days (.17 of a month) for each additional year of the elder's age.

### ***Continuity of In-home Use***

The findings related to continuity of in-home respite use over the period of eligibility are reported in Table 2.16. The variance components in the lower panel of the table indicate that variation in continuity occurs between individuals and across providers. As was true for duration, characteristics of the providers were not associated with continuity. In fact, continuity was found to be related to only two of the many variables investigated (geographic residence of the elder and the level of impairment of ADL). The intercept coefficient indicates that the continuity of in-home respite use was .66 for elders with no ADL impairment and who resided in urban settings. Elders residing in rural areas used in-home respite more continuously over the time that they were eligible for services than did elders in urban areas. The continuity score for elders residing in large cities was .07 lower than for those in a rural setting and the ratio for elders in small cities (population between 2,500 and 50,000) was .02 less than that of elders in rural settings. In contrast, the continuity ratio was .03 higher for elders residing in small towns (population less than 2500 population) than for those in rural settings. Continuity increased by a small amount (+.005) for each point increase in the level of ADL impairment.

**TABLE 2.16 IN-HOME RESPITE: CONTINUITY OF USE**

<u>Fixed Effects</u>	<u>Effect Prob.</u>	<u>Coefficient</u>	<u>Std. Error</u>	<u>t Ratio</u>
Intercept		.662	.028	24.00
<b>PERSON VARIABLES</b>				
<b>Geographic Location</b>	.0103			
City or Suburb (> 50,000)		-.072	.030	-2.42
Smaller than city but > 2,500		-.017	.022	-.073
Town < 2,500		.031	.024	1.30
Rural Setting		0		
<b>ADL Score</b>	.0234	.005	.002	2.27
<u>Random Effects</u>		<u>Variance Comp.</u>	<u>z-Value</u>	<u>Prob. Of z</u>
<b>LEVEL ONE</b>				
Individual Variation		.056	23.45	.0001
<b>LEVEL TWO (Client within Provider)</b>				
Provider Initial Status		.013	3.30	.0005

### ***Intensity of In-home Use***

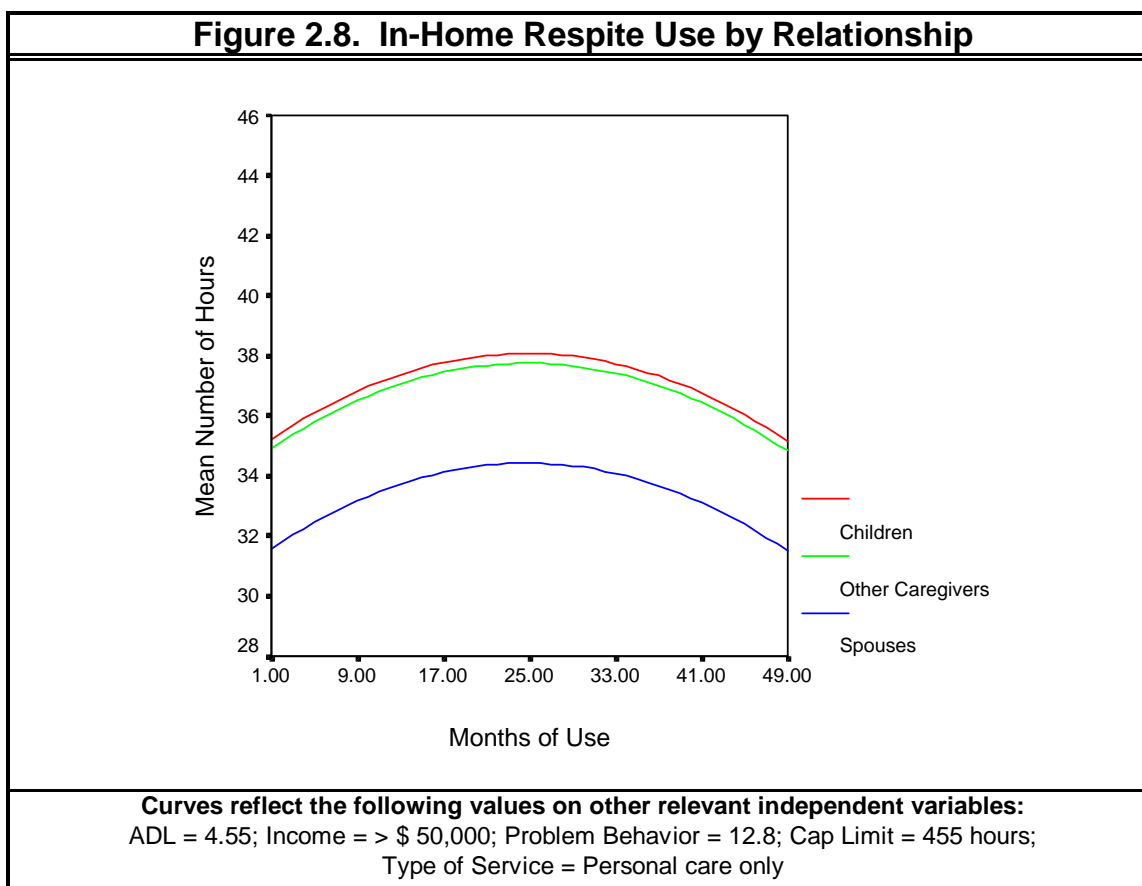
**Variation Use Over time and Across Providers.** Results of the longitudinal analysis of in-home use are shown Table 2.17. The variance components for the random effects shown in the bottom panel reveal patterns that reflect significant variation in all components. The variance component for level 1, which is labeled “temporal variation” indicates that the number of hours of in-home services used by each client varies over the duration of use. The level 2 variance component labeled “client initial status” indicates that there is significant variation in the number of hours of respite at the time of initial use among individuals served by the same provider. The second variance component reported under level 2, which is termed “client rate of use”, indicates that there is also significant variation across clients in their patterns of increase or decrease in hours of service used over time. The level 3 variance component for “provider initial status” indicates that there is significant variance across providers in the average number of hours used by their clients. The second variance component reported for level 3, which is labeled “provider rate of use”, is small but statistically significant. This indicates that the patterns of change in in-home respite use also differ significantly across providers.

**TABLE 2.17 IN-HOME RESPITE: INTENSITY OF USE**

<u>Fixed Effects</u>	<u>Effect Prob.</u>	<u>Coefficient</u>	<u>Std. Error</u>	<u>t Ratio</u>
<b>Intercept</b>		11.271	3.820	2.95
<b>TIME</b>				
<b>Linear</b>	.0140	.248	.101	2.46
<b>Quadratic</b>	.0023	-.005	.0015	-3.05
<b>PERSON VARIABLES</b>				
<b>Relationship</b>	.0021			
Child		3.649	1.073	3.40
Other Relationship		3.330	1.555	2.14
Spouse		0		
<b>Income Group</b>	.0034			
Under \$5,000		-2.862	3.578	-.80
\$5,000 - \$15,000		-1.895	3.402	-.56
\$15,001 - \$30,000		-.581	3.455	-.17
\$30,001 - \$50,000		5.613	3.749	1.50
Over \$50,000		0		
<b>ADL Score</b>	.0092	.425	.1630	2.61
<b>Problem Behavior</b>	.0002	.251	.068	3.72
<b>PROVIDER VARIABLES</b>				
<b>Cap</b>	.0001	.017	.003	5.62
<b>Type of Service</b>	.0094			
Social/Companionship		4.408	2.653	1.66
Personal Care Only		10.001	3.314	3.02
Both Companionship and Personal Care		0		
<u>Random Effects</u>		<u>Variance Comp.</u>	<u>z-Value</u>	<u>Prob. Of z</u>
<b>LEVEL ONE</b>				
<b>Temporal Variation</b>		180.95	67.21	.0001
<b>LEVEL TWO (Client within Provider)</b>				
<b>Client Initial Status</b>		226.31	19.17	.0001
<b>Client Rate of Use</b>		.887	8.30	.0001
<b>LEVEL THREE</b>				
<b>Provider Initial Status</b>		21.910	2.40	.008
<b>Provider Rate of Use</b>		.162	1.86	.031

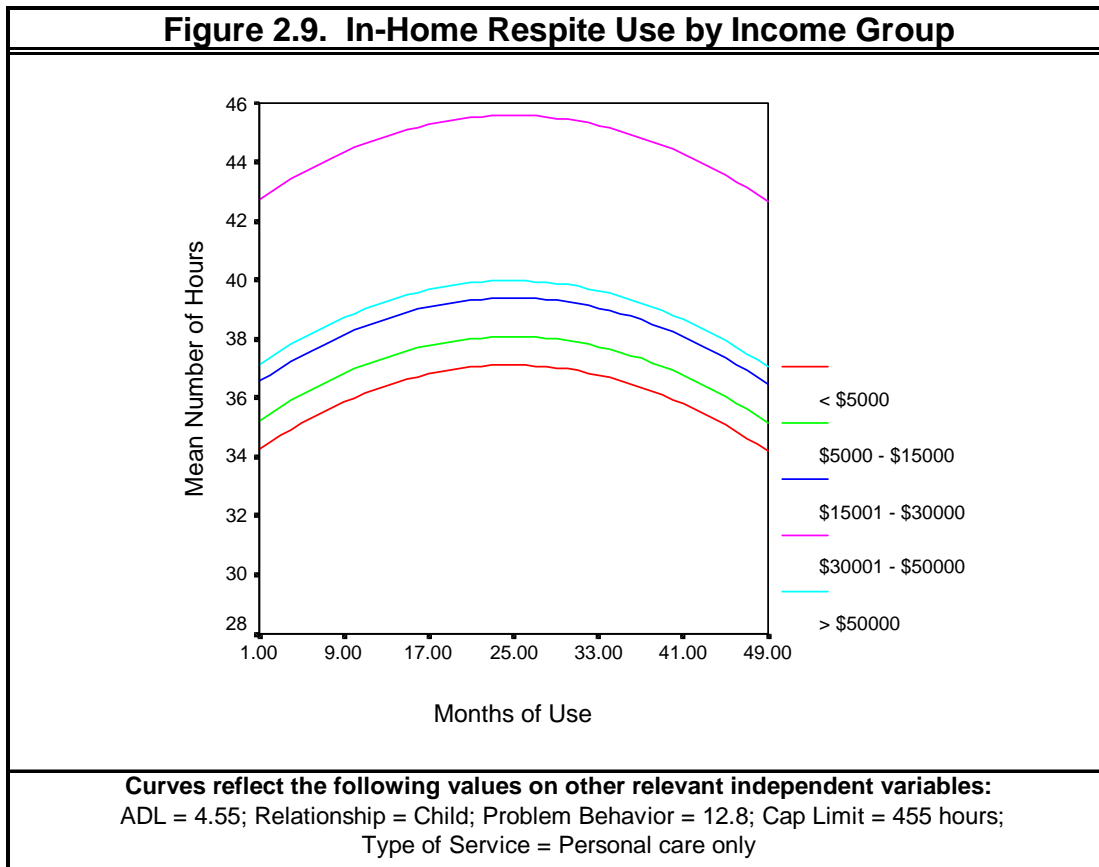
The coefficients reported in the top panel of Table 2.17 provide information about the intensity of in-home service use at the onset and the change of intensity over the duration of use. The coefficients for the linear and quadratic components are both statistically significant, indicating a

pattern of change in respite use that can be described as a shallow inverted U-shaped curve. This curve was found to be consistent across all segments of the sample and is shown in Figure 2.8 for the three types of caregiver relationships. All differences in the level of in-home service use observed across segments of the sample were associated with differences in the initial level of service use.



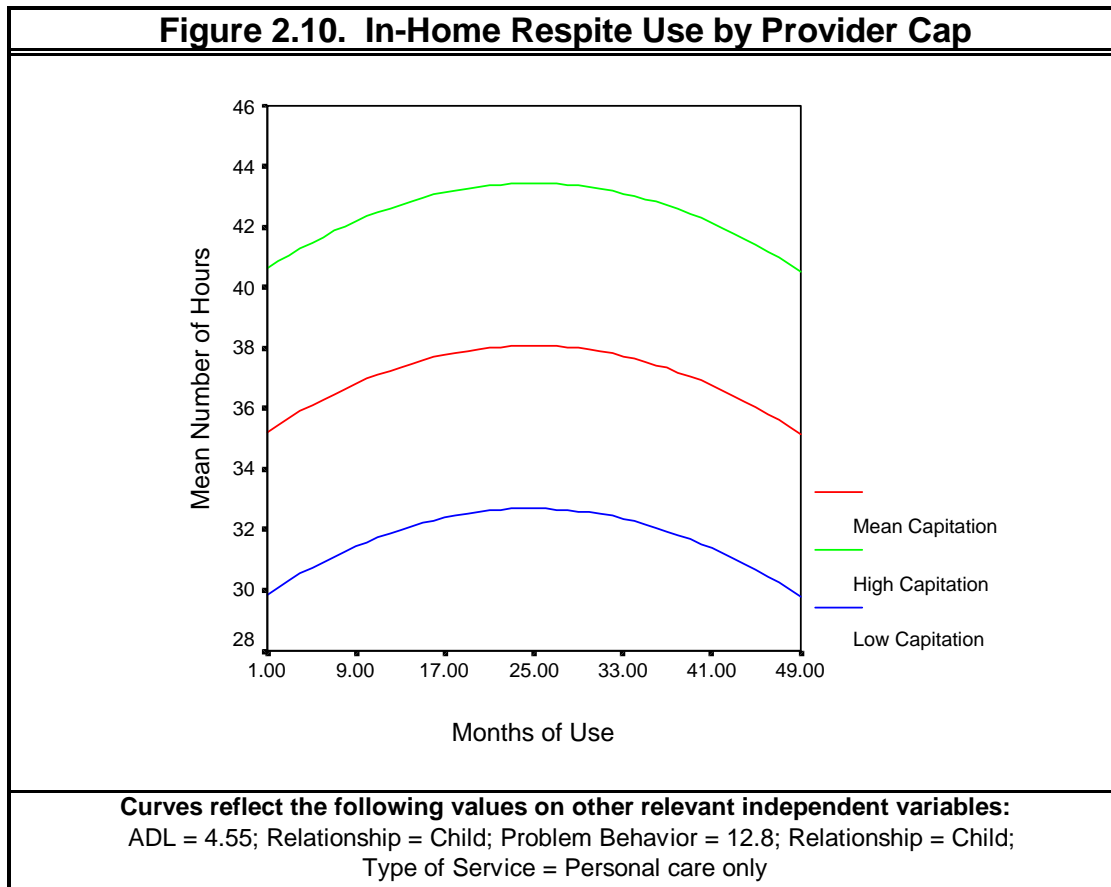
The coefficient reported for the intercept (referent group) indicates that an elderly client will use 11.27 hours of in-home respite service if he or she is: (1) cared for by a spouse, (2) has an income over \$50,000, (3) has no impairment in ADL, (4) exhibits no problem behaviors, and is being served by a program that (5) provides both social and health services. For this analysis, the service cap was centered at 50 hours of use per year, which is the lowest cap set by a provider in this sample. Elders cared for by an adult child used 3.6 hours more per month and those cared for by a more distant relative will use 3.3 hours more service.

As depicted in Figure 2.9, the number of hours of in-home service used by clients is also related to client income. This relationship, however, is not linear. The group that used the highest number of hours of in-home services was in the middle-income group that earned between \$30,000 and \$50,000 dollars. This group used an average of 5.6 hours more service than did the high-income group (over \$50,000 per year). The other three groups, which include the lowest income groups, did not differ significantly from the high-income group. This curvilinear pattern is of special interest because it is the opposite of the pattern that has been frequently observed for nursing home placement. In contrast to the pattern of greater use of in-home services observed for middle-income clients in this study, studies of nursing home placement report less use of nursing home care by this group and higher use of nursing homes by both the low-income and high-income groups. In combination, these patterns suggest that middle-income clients do, indeed, use respite care as a mechanism for avoiding nursing home placement.



Increased impairment in ADL and higher prevalence of problem behaviors are both associated with more intense use of services. The numbers of hours of in-home service used by clients increased by .43 for each point increase in ADL and by .25 hours for each point increase in the problem behavior measure (Table 2.17).

On average, clients served by agencies providing only personal care services used ten more hours of in-home care per month than did persons who received care from an agency offering both companion care and personal care services. It is also the case that clients served by programs that offer only social or companion services used 4.4 more hours of service than did those who were served by agencies offering both personal care services and companion care. Finally, as was true for day care, the limitation or cap placed on service availability by the provider was associated with the number of hours clients used services. For each additional hour allowed by the provider, the average monthly service use by clients was .017 of an hour higher, as shown in Table 2.17 and illustrated in Figure 2.10.



## DISCUSSION

Several general trends can be identified from the findings detailed in this study. Most importantly, the analyses underscore the fact that characteristics of the elder, the caregiver, and provider are all associated with patterns of respite use. However, the influence of each of these sets of characteristics varies depending upon the definition of use and which measure of respite use is examined.

### Brief Use

The decision of a caregiver to continue or discontinue use of services after an initial trial period appears to be most related to the characteristics of the service provider. The analyses that identify characteristics of brief users suggest that caregivers make judgements about the appropriateness or usefulness of a respite program for their caregiving situation and then act in accord with this judgement. The provider characteristics identified as predictors of continued day care use provide an interesting picture. The positive correlation between problem behavior and brief user status indicates that the day care programs do not accommodate elders who frequently engage in problem behaviors and therefore these elders quickly discontinue using day care. In contrast, the longer periods of respite offered by day care programs as opposed to in-home programs are useful for caregivers who are employed full time. Employed caregivers can use day care as a long term care option that enables them meet their work obligations while simultaneously retaining primary responsibility for the care of the elder. This conclusion is supported by the fact that the level of service capitation is negatively related to brief use. Programs offering longer hours of care enable working caregivers to continue using day care services. Finally, the higher concentration of minority caregivers who continue to use day care suggests that the providers offering these services as part of the ADDGS project were successful in conveying their openness and accessibility to these diverse groups.

When considered together, the factors that predicted brief use of in-home services reflect the preference of caregivers who initially seek in-home services for higher levels of care that are best offered by well-trained professionals. Users of in-home respite tend to discontinue use of programs that are staffed by volunteers and do not provide assistance with personal care tasks.

### **Sustained Use**

In contrast to the provider characteristics that predict brief use, client characteristics are the primary predictors of the *duration* of respite use and the *continuity* of service use once the decision has been made to continue using services. Both ethnicity and the client's use of both types of respite services are associated with duration of use. As a group, Black/African-Americans use day care for a longer period time than any other group. They also use in-home services for a period similar to that of Hispanics/Latinos and longer than either Whites or persons from other ethnic groups. This pattern suggests minority groups will use services and will continue to use services once they judge the service to be appropriate for their needs. The fact that clients who use both in-home and day care services tend to use each service for shorter periods of time, suggests that clients who have the option of using multiple services shift from using day care to using in-home care when there are significant changes in the elder's level of functioning or their caregiving context. That is, when clients have a choice of types of respite care, they are better able to match services to their needs throughout their caregiving career. This interpretation is supported by the additional finding that level of IADL impairment is negatively related to duration of day care use. To summarize, as long as elders are able to function in a day care setting, they continue to use that service. When elder impairment becomes too high, families are likely to seek in-home services.

The changing needs of individuals are also linked to patterns of *continuity* of service use. Of note is the fact that the level of ADL impairment is *positively* related to continuity of in-home service use but *negatively* related to the continuity of day care use. Clearly, persons with high levels of ADL impairment are not well served by day care programs, but high ADL impairment scores indicate a need for regular in-home care. The fee structure is the only provider variable that is related to continuity of use of day care services. When families are required to pay part of the costs of care they tend to use services less frequently.

Together these diverse findings about predictors of brief user status, *duration* of respite use and continuity of respite use underscore the differences in the kind of support that is afforded by each type of respite. Day care is most often used as a support system when caregivers must be away from the home or when caregivers have other obligations that require their attention. In this capacity, day care allows caregivers to retain responsibility for the care of the impaired elder

while meeting other work and family obligations. However, when the impairment level of the elder increases to higher levels, caregivers must make an important lifestyle decision. For adult children who cannot leave a parent at home alone, that decision may well be to cease caregiving. Clearly, a greater number of spouses continue to provide care when day care is no longer appropriate for their level of need. Consequently, spouses are more frequent users of in-home respite care.

Both client and provider characteristics are related to the number hours of respite used on each occasion and to changes in the intensity of use over time. The influences of four types of caregiver characteristics are particularly informative. First, the client characteristic most consistently related to the quantity of respite use is the caregiver's relationship to the elder. In general, elders who are cared for by spouses use significantly fewer hours of respite care than do their peers who are cared for by an adult children or other more distant relatives. The number of hours of day care used also varies significantly with the gender of the caregiver. Elders with male caregivers use more respite services.

The functional level of the elder is also clearly related to the amount of respite used. Among users of in-home respite, higher levels of ADL impairment and problem behaviors are associated with greater use of services. Because elders using day care tend to have low ADL impairment, day care use is most related to level of impairment in IADL. Although high levels of IADL are associated with a shorter duration of day care use, high levels of IADL are also associated with greater continuity of use and more hours of use on each occasion. Moreover the number of hours of use during a month increases with duration. This pattern of associations further underscores the fact that day care programs serve a different segment of the caregiving population than do in-home respite programs.

Ethnicity is also an important predictor of levels of respite use and this association between ethnicity and use is a complex issue. Different ethnic groups have distinct trajectories of service use over time. Although Black/African-American elders use day care for a longer duration period than does any other group, the amount of day care used each month diminishes over time to a point that they become the group with the lowest level of use after an extended period of use. In contrast, as a group, Hispanic/Latino elders use day care for the shortest duration

period, but their level of use is the highest of any ethnic group at the time of initial use. Also, they maintain this higher level of use relative to Whites and Blacks/African-Americans throughout the duration of their use. Clearly, the pattern of day care use for Hispanics/Latinos is distinct from that of both Whites and Blacks/African-Americans, but the two groups do not differ in the total number of hours of day care use. Blacks/African-Americans tend to use smaller quantities over a more extended period of time, while Hispanic/Latino elders use high quantities for short periods.

Finally, income is a significant predictor of use of in-home services. The highest level of in-home service use is observed for middle-income elders who tend to have little discretionary money but who are not eligible for Medicaid. This is the group that is least likely to place an elder in the nursing home. Consequently, it is not surprising that they are the highest users of in-home respite. For them, in-home respite is probably the most economical solution for long term care.

Two provider characteristics influence service use for both types of respite services. As would be expected, the amount of service for which a client is eligible clearly influences the level of service use. In addition the level of care that a program provides is related to the amount of respite use. The higher level of service among clients of programs that offer health related or personal care services is consistent with the notion that families seek more intense services when elders have higher levels of need.

The association observed between level of service capitation and the level of use deserves serious attention. This connection suggests that providers that cap services may not be effectively distributing their resources among clients with different levels of need. If services were being used in accord with client need, the level of individual use should not be related to provider caps.

### **Practice Implications**

The findings from these analyses are very extensive and can be used by policy makers and providers to guide the development and delivery of support services. A small number of

implications are identified here for consideration.

First, the findings underscore the importance of using multiple definitions of use when creating profiles of respite use for different segments of the target population. Accurate estimates of the cost of respite cannot be made without clear knowledge of the duration, continuity, and amount of respite use over time.

Second, when planning and budgeting for respite services, providers would be wise to pay close attention to the characteristics of their client pool. Clearly, there are differences in the type of services used and the patterns of service use that are associated with the relationship of the caregiver to the elder, the ethnicity of the caregiver, and the functional levels of the elder. All of these factors will influence the type and quantity of services that should be made available and ultimately, the costs of these services. Moreover, differences among these segments of the target population create an imperative for offering multiple forms of respite to meet their different needs and to continue to provide support as the needs of individual families change over time. This analysis provides solid evidence that in-home respite programs serve a very different population than do day care programs.

Finally, the findings from this study should prompt providers to consider carefully the levels of care they provide and any limitations on the amount of services that are provided to a client. When providers offer only the lowest levels of care, many families will be unable to use respite services. Similarly, when providers cap the level of service use for all clients, they may not be distributing their resources in the most effective manner. Limitations placed by providers on the level of care offered, and the amount services made available to clients, are likely to create significant barriers to appropriate use of services. Many clients will go unserved, others will be underserved, and still others may receive an excess of service. The effective targeting of resources will require close scrutiny of characteristics of the target population and development of multiple levels of respite care.

## ENDNOTES

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- <sup>1</sup> Initially, a model including two dichotomous variables representing the type of day care program (i.e. ADC only, Group Day only, or Both types of day care) was tested. However, the findings from that model did not differ significantly from the more parsimonious model depicted in Table 2.7 which was parallel to the model used to predict brief use of in-home services.
- <sup>2</sup> This analysis proceeds by “centering” the data on a **referent profile** and calculating the variation for other profile components from that referent profile. That is, for Table 2.12, the data is centered on White unemployed caregivers who care for an elder with no IADL impairment and who only used day care. The referent profile can be identified by the zeros in the coefficient column. (0 represents that there is no variance from the referent profile—they are one in the same.) Thus, the **coefficient** for the **intercept** at the top of the table, 20.435 represents the average number of hours of day care use by the referent profile. To identify the average hours for other profiles, one adds or subtracts the appropriate coefficients. For example, a Black/African-American (coefficient 4.275) who is employed full-time (coefficient 2.417) who used both respite services (coefficient -3.736) would have an average use profile of 23.391 hours [20.435 (referent profile) + 4.275 (Black/African-American coefficient) + 2.417 (employed full-time coefficient) – 3.736 (used both respite services coefficient) = 23.391 hours.
- <sup>3</sup> Findings for these analyses are available upon request.

# **UNDERSTANDING CULTURAL BARRIERS TO SERVICE USE**

**ADDGS STAFF INTERVIEWS**

**STUDY THREE**

## EXECUTIVE SUMMARY

### STUDY THREE:

#### QUALITATIVE INTERVIEWS WITH KEY DELIVERY STAFF TO DOCUMENT SUCCESSFUL STRATEGIES FOR ADDRESSING CULTURAL BARRIERS TO SERVICE USE

### OBJECTIVES

The primary purpose of this study was to explore more fully the ethnic, geographic and familial contexts of service from the perspective of service providers. To a large extent, the success that providers experienced with developing and implementing culturally appropriate support services appeared to reflect their insights into the cultural contexts of the families that they served. This qualitative study was designed to more fully capture these understandings of staff members through in-depth interviews. These experiences and perceptions of staff members are valuable for interpreting and corroborating findings from the quantitative studies.

### METHODS

Fifty qualitative interviews were completed. Forty-two interviewees were frontline staff members and eight were administrators. Interviews were conducted by telephone and then tape recorded for later transcription. Questions followed the Interview Guide and proceeded in an open ended, in-depth format in accordance with qualitative methodology. Upon completion of the transcription of the interviews and assurance of their accuracy, the full analysis was undertaken.

### RESULTS

Providers from the ADDGS project offered specific and detailed advice for those who wish to develop acceptable and appropriate services for diverse populations. Additionally, staff members, as a group, made several general recommendations that are pertinent to all programs, regardless of the cultural groups that comprise their client populations.

#### **General Lessons for Service Delivery**

- Become familiar with your service community!
  - Get to know both the culture and language of the community.
  - Become aware of other available resources and services.
  - Understand the issues related to service use, such as socio-economic levels, education, employment status, and other key factors.
  - Understand family structures and caregiving beliefs.
- Develop Appropriate and Responsive Service Programs!
  - Use culturally appropriate materials and activities.

- Hire and train bicultural staff members (from the community if possible).
  - Individualize care plans when possible.
  - Match hours available to caregiver needs.
  - Create homelike environment with friendly, welcoming staff.
  - Use “socializing” context for support groups.
  - Use “sliding fees” to negate “welfare” stigma.
- Build trusting relationships!
  - Stress honesty in interactions.
  - Create clear expectations for care with clients.
  - Follow through! Follow through! Follow through!
  - Recognize and reward excellent staff members.
  - Hold Team meetings so all staff members can provide input.
- Educate the Community!
  - Provide information about Alzheimer’s disease.
  - Let families know about the purpose and availability of respite services.
  - Explain about the value of dementia-specific services.
  - Inform how support services can enhance family care.

Providers also shared issues and advice unique to specific cultural groups. These service aspects, they are quick to add, are second to developing a caring, compassionate service. Understanding the community and building trusting relationships can overcome differences. However, special attention to some of the unique needs of the various cultures can smooth the transition for new service users and ensure greater satisfaction of all users. Providers offered the following lessons.

#### **Lessons for Rural Communities**

- Creativity, flexibility, and innovation are needed to address isolation, transportation needs, and lack of resources.
- Respite should be promoted as an support for, not a replacement of, family care.
- Charging a small fee can address the welfare or handout stigma.
- Focus on empowering clients in their relationships with medical professionals.
- Assign familiar aides to families when possible.

#### **Lessons for Black/African-American Communities**

- Work with key community leaders to develop trust with residents.
- Address the needs of working caregivers.
- Promote respite as an aid to, not replacement of, family care.
- Create a social atmosphere, preferably with food.
- Match workers and clients by race when possible.

#### **Lessons for Hispanic/Latino Communities**

- Develop bicultural expertise in staffing.
  - Mirror the community, ethnically and culturally when possible.
- Incorporate folk medicine into educational approaches.
- Educate about the medical aspects of Alzheimer’s disease.
- Providing familiar food and activities can create more comfortable environments.
- Reassure caregivers that they are not alone.
- Assure caregivers that using respite is not selfish or neglectful.
- Create social, friendly environments for service provision.

**STUDY THREE:**

**QUALITATIVE INTERVIEWS WITH KEY DELIVERY STAFF  
TO DOCUMENT SUCCESS STRATEGIES FOR ADDRESSING  
CULTURAL BARRIERS TO SERVICE USE**

**INTRODUCTION**

Prior to the Alzheimer's Disease Demonstration Grants to States project (ADDGS), the majority of support services delivered to families of individuals with Alzheimer's disease were directed to urban, White, middle class populations. Likewise, most scholarly work concerned with Alzheimer's disease caregiving and service provision was also similarly narrow in its focus (Tennstedt et al., 1998). The few studies that did attempt to address the omission of minority populations failed to differentiate adequately among minority groups, often treating all nonwhites as a homogenous group (Bass et al., 1992). While this approach provided some insight about urban, White, middle class communities, there were still significant gaps in the service populations, knowledge, and literature. The ADDGS project was developed to specifically address this limitation by funding both service provision for, and research on, support services to ethnically diverse families.

Through the demonstration, many lessons about how to serve diverse Alzheimer's populations have been learned. The quantitative data collected has provided a wealth of information about "who" uses "what" and "when". Whereas previous, interviews with caregivers have identified the key elements for client satisfaction with respite services (Montgomery et al., 1997). From the site visits and conversations with frontline providers, the variety in cultural expectations and the similarity in care issues for Alzheimer's families have been noted. Thus, the ADDGS has broadened the intellectual understandings of the differences in serving families of ethnically, geographically, and familial diversity while highlighting the analogous care needs of families of individuals with Alzheimer's disease.

To serve diverse groups effectively, it is important to understand clients within their ethnic, geographic, and familial cultural contexts. It is essential to identify cultural differences in caregivers' beliefs about Alzheimer's disease and medical care, social norms, views of "helping" agencies, and formal service utilization expectations for care provision from family members. However, it is also important to realize that within these diverse cultural contexts, the families'

care needs are disease driven and, thus, their service needs for support may not be equally diverse. This is demonstrated by the commonality of respite services—though not their delivery mechanisms--offered through the ADDGS project.

Since its inception in 1992, the ADDGS project has been delivering services to many hard-to-reach and under-served populations. In order to do this successfully, service delivery staff members have learned about their target populations' needs and expectations. They have also identified existing barriers to be addressed. Project staff has also developed innovative service delivery approaches to reach these new populations. This study of the research project was undertaken to document these insights from the perspective of local delivery personnel.

### **Caregiving and Cultural Context**

Caregiving is a dynamic process that is accomplished within a cultural context with attendant meanings, symbols, and rituals for the participants. More than merely attitudes and behaviors, caregiving is a process that emerges out of a previous relationship that varies with regard to generation, gender, and individual family histories. Even when non-family members perform caregiving tasks, their cultural understanding of the process as well as previous individual experiences influence each participant--the caregiver and the care recipient.

It is currently estimated that over 6.7 million elderly individuals need some form of assistance with one or more ADLs or IADLs (Hing & Bloom, 1990), though others place the estimate even higher (Ory & Duncker, 1992). Indeed the number of individuals over the age of 65 in the United States is predicted to double within the next four decades and the "frail elderly", those over 85 years of age, will represent the largest percentage increase (Sterneck, 1990). More assistance will be provided to these elders than ever before (Longino et al., 1990). While most of these individuals rely exclusively on help from family or other informal (non paid) persons, these networks of informal support are generally weak (Wilcox & Taber, 1991). Thus, there is a growing percentage of elderly who either exhaust or do not have these familial resources and, in turn, come to rely on paid formal caregivers for all their essential needs (Lyons & Zarit, 1999).

Formal homecare workers often fill that gap between family support and elder need. As individuals age or become incapacitated due to illness or disability, many are seeking and using assistance from home-based services as a preference to institutionalization. In-home respite care is the most frequently required (Wallace, 1990) and requested form of formal assistance

(Montgomery & Kosloski, 1995). Indeed, families caring for cognitively impaired elders identify respite care as one of their core needs (Lawton et al., 1989; Friss, 1990; Petty, 1990). A study of 85 year olds or older in the community noted that nearly half (49.5%) needed assistance due to functional limitations (Hobbs, 1996). Others project that currently, for every person institutionalized for care, there are four or more individuals in the community requiring some form of *formal* long term care (Ory & Duncker, 1992).

These projected needs are further complicated as one notes that the United States is experiencing a demographic shift from a predominately White, European population to a multi-ethnic, multi-cultural society (Zinn, 1995). This is likely to lead to an even larger percentage of elderly individuals with functional and other care needs due to the differences in health and social status. Black/African-Americans and Hispanic/Latinos have lower socio-economic levels than their White counterparts (Taeuber, 1993). This results in general states of poorer health with greater functional disabilities for Black/African-Americans and Hispanic/Latinos (Wallace et al., 1994;). In spite of this increased need for assistance, Black/African-Americans and Hispanic/Latinos are often under represented in service utilization (Kemper, 1992). However there is evidence that these populations do use services when services are provided in culturally appropriate ways (Montgomery et al., 1997). In fact, Wallace et al. (1994) found no difference in use rates between Latinos and Whites.

### **Study Purpose**

The primary purpose of this study is to explore, in a more thorough manner, the differences found among cultural groups in the larger evaluation project (Montgomery et al., 1997). This qualitative study was designed to corroborate as well as to interpret the quantitative findings by seeking perceptions and insights of staff members for developing and implementing culturally appropriate support services for diverse populations. In other studies the insights of service staff have been found to be profoundly helpful and instructive in understanding the care delivery process as well as discerning how to best provide useful, efficient, quality services (Karner et al., 1998; Karner, 1999).

## **Methods**

### ***Sample***

Fifty interviews were completed. Of those, forty-two interviews were conducted with frontline staff members and eight were conducted with administrators. Fifteen of these staff members worked for programs that targeted urban dwelling Hispanic/Latino families and ten served urban Black/African-Americans. Of the twenty-five staff members working in programs that served rural populations, eight worked to provide respite to Black/African-American families while four served rural Hispanic/Latinos. The remaining thirteen staff members were employed in programs that served rural families of all ethnic groups. (See Appendix 3.A).

### ***Interview Process***

Initially, letters were sent to the state coordinators of the eight selected demonstration states requesting them to identify eight to ten staff members appropriate for interviews. Since the purpose of these interviews was to document successful strategies for serving diverse populations and to identify culturally specific needs, coordinators were asked to identify staff members who had at least one to two years of experience with the demonstration project. Appropriate staff members would also have a broad understanding of the cultural needs of the target population, and knowledge of the various ways the program had attempted to serve them—both those that were successful and those that were not. Ideally, staff members would be actively involved with targeting and serving under represented populations. Sixty-nine staff members were identified and their names and contact information were forwarded to the University of Kansas team.

A letter providing information about the study and the anticipated format of the interviews was sent to each of the identified staff members (see Appendix 3B). Staff members were informed that the interviews would be an effort to systematically compile some of the field expertise developed through the demonstration project. Furthermore, the interviews were to capture the “how to” information needed to create or replicate successful programs elsewhere. The interviews were scheduled to be completed in approximately one hour. Approximately two weeks after receiving the letter each staff member was contacted by The University of Kansas Interviewer who answered any questions the respondent had about the study and then scheduled an interview with those persons agreeing to participate.

Interviews were conducted by telephone and then tape recorded for later transcription. Questions followed the Interview Guide (see Appendix 3C) and proceeded in an open ended, in-depth format in accordance with procedures of qualitative methodology. This methodology focuses both on language and interpretation of the respondents—that is, it is not only the answer given that is considered as data, but the meaning that is attached to the answer by the interviewee is also important. This orientation is particularly appropriate for research such as this, which focuses on the identification of cultural, geographic, and familial beliefs. The qualitative approach “emphasizes the relationship between personal experience and the historical, social, and cultural contexts—the link between people and settings, self, and society” (Riessman, 1990: xii).

When appropriate, follow up questions were used to elicit further specificity in the responses. This method of interviewing allows the respondents to be integral participants in the interview process. By using their own words (as opposed to response categories), interviewees use their own cultural views and meaning structures to respond. Additionally, they may “lead” the interviewer into topics that may have been overlooked, yet have significance. This can aid the researcher in understanding the issues more broadly.

### **Analysis**

Following the tenets of qualitative methodology, the analysis proceeded through a series of stages (Lofland & Lofland, 1984; Glaser & Strauss, 1967), beginning with the transcription and reporting of the interviews without any analytic frame. The data were then read thoroughly for emerging themes, connections and main concepts. This constituted the *rudimentary* classification of the major subjects of interest (Charmaz, 1988; Strauss, 1987). For this project, the rudimentary classifications were framed by the proposed research questions. The next analytic phase sought to *refine* the classifications further into conceptual categories. These categories are organized by the research question topics. At this point, the text data was further ordered by pertinent issues within the research question. By referring to the staff members’ own phrasing and terminology, the analysis can facilitate clearer understanding among providers and offset any potential error due to research jargon.

### **Research Questions**

In order to gain the most insight about service delivery barriers and successful strategies used to address them, a broad, open-ended format of questions was used. Specific study questions to be answered include:

1. What are the special characteristics of the target service population?
2. What is the prevalent view of Alzheimer's disease in the target population?
3. What is the prevalent view of using support services in the target population?
4. How willing are members of the target population to receive services from staff of different backgrounds?
5. What barriers to service use have been identified for the target population?
6. How has service delivery been modified to address identified barriers? Have these efforts been successful?
7. How has staff hiring or training been modified to address the needs of the target population?
8. What are the key components to successfully provide respite services to the target population?

### **RESEARCH QUESTION #1: WHAT ARE THE SPECIAL CHARACTERISTICS OF THE TARGET SERVICE POPULATION?**

This study focuses on three populations served by the demonstration: Rural, Black/African-Americans, and Hispanic/Latinos. Each population has its own history in the United States and its own culture. The uniqueness and special characteristics of each group is highlighted and discussed below.

#### **The Lost Ones—Rural Communities**

I call them the **lost ones** because ... most of them are the farmers in rural counties who have worked real hard all their lives and they are faced with the choice of either giving up everything they have or surviving (35, emphasis added).<sup>1</sup>

The rural demonstration projects, included in this research, have served extremely isolated rural communities in northern Maine and the Upper Peninsula in Michigan as well as agricultural communities in North Carolina, South Carolina and southern Florida. Clients who live in rural areas are thought to face specific logistic barriers in accessing services. The demonstration, however, has brought the importance of understanding the cultural aspects of rural communities to the forefront. Staff members are quick to point out the unique aspects of living in a remote areas and small communities.

In rural areas, one provider tells us, “people are more apt to stay on their little fifteen acres of land and take care of their problems on that side of the hill” to illustrate the self sufficiency and social isolation that are prevalent (31). Another staff member believes that it is the sense of privacy and independence that contributes to the belief that rural folks try to take care of their own by themselves. “They’ve been through a lot of hard times,” she continues, “and they have pride in the fact that they’ve been able to go through these times and do well” (18). Another staff member agrees,

I think there is a lot of pride in being hard-working and strong and well. When someone in the family gets Alzheimer’s ... [They think] they can do it themselves. Or when they have to ask for help, they think they may be somewhat of a failure, that they should have been able to do it themselves (23).

This belief that asking for help is admitting that they have failed is particularly strong with spouse caregivers.

I took a vow 65 years ago that I will stand by this woman, or this man, for better or worse, until one of us is gone, and that’s what I’m going to do.” And they might start crying, because they feel that they’re breaking that [vow] by bringing me in, or bringing my volunteers in, because **they** should be doing that. “Nobody can take care of my husband” (27).

Family relationships play a central role in rural communities according to providers. “I see a lot of family caring, people pulling it together the best they can” states one staff member (21).

Another provider explains that family priorities are very strong and different than she believes exist in non-rural areas.

I think that their priorities are different. Their priorities are usually centered around the family. They’re very family oriented, family focused, and work oriented. A lot of people up here do not have a hobby (18).

This sense of family and family expectations runs throughout the interviews with rural providers. A client told a provider, “You have to do that because mom and dad has taught us that’s what you do, you take care of each other” (30). The expectations for family also include the notion of privacy. “They are private people, and they’re not used to expressing family matters” (41).

Churches also play a key role in rural communities. A provider in South Carolina explains that the church is the focal point of the town (36). It provides a “glue” that holds groups together. Rural churches also serve as extended family in some communities. The churches can be the community lifelines (21). One provider paraphrases the church in her community as saying, “This is our family, this is our job, [and] it’s a big job” (27).

General isolation can play a role in enhancing the tendency to pull together as a family, church, and community. Many clients live several miles from the nearest store, and basic services like paper delivery do not exist (27). This translates into a greater dependency on those around you or as a particularly remote provider points out, a great dependency on one's car and one's ability to get to town for services, information, and health care. "Our agency serves four counties and they are very rural... People depend on their cars, and ... you know that many folks as they age are not able to continue to drive very far" (21).

Providers tell us that individuals from rural areas often have less education so literacy is a common issue especially for elderly rural. Many do not have access to medical services on a regular basis, while others are very loyal to their family doctors and do not see a need for specialists or advanced assessments (28). However, if the clients are adult children caregivers, staff report that they are more likely to be educated, interested in gaining information about Alzheimer's disease and using services (27).

Language is also a unique problem in upstate, rural Maine as many individuals speak only French or very little English. One provider explains, "They have been so intent on preserving their language that many of the older people refuse to speak English" (18). Additionally, she continues, that there are "a lot of negative comments about the French people... they're perceived as less intelligent [because] they have more of a difficult time expressing themselves" (18). Thus she has to address the subtle prejudice as well as the language barrier. Unfortunately, this is not only an issue in Maine. In another area, a staff member explains, "there's a lot of bigotry going on in this area" (28). She continues to warn that it is "well hidden, the prejudice in this area" (28).

In general, the rural residents who receive demonstration services share characteristics unique to their geographic location. Isolation has led them to rely on themselves, and take pride in their self-sufficiency. Family relationships play an important role in the lives of rural citizens, and family members often feel a resultant duty to care for sick members. The church also occupies a central place, functioning to hold communities together.

Rural residents have had relatively few educational opportunities. They have been similarly limited in their access to regular medical care, although this is less so for adult children

caregivers. Even though rural areas are more homogeneous than many urban areas, discrimination based upon ethnic origin exists in rural areas, only in a more covert form.

### **Strong Extended Families -- Black/African-American Clients**

The Black/African-Americans served through the demonstration come from a variety of backgrounds and cultures. In the southern states of North Carolina and South Carolina, the Black/African-American communities are descended from the days of slavery and have a culture that reflects that history. In Michigan and the District of Columbia, the Black/African-American communities developed through the northern migration of southern blacks for industrial opportunities after WWII. Whereas the Black/African-Americans served in Florida are often the more recent first or second generation immigrants from Haiti, the Bahamas, and the Dominican Republic who came in search of a better life and went to work in the fields. Each of these communities has a distinctive worldview that has been influenced through diverse experiences.

Even though they are African-Americans, there is diversity. ... You cannot use one broad stroke to paint all African-Americans, so that even within the older population, there are differences (38).

This diversity has prompted providers to remember, "Every family is different. You can't totally generalize" (11). Though staff members do observe that family and community relationships are strong in Black/African-American communities. "I'm going to say that we're more family oriented, because we want to keep everything in the family" (16), states one staff member. Another provider concurs, Black/African-Americans "sort of take in each other" (14). The women in the family seem to be at the core of this cohesion and caring.

It's also a female dominated caregiving community in many, many ways. The daughters and the wives are major caregivers. It sounds kind of hokey but music, ties to church, family meals, laughter—It all seems to be a part of the culture (43).

This inter-family caregiving extends to older persons. The "extended family ... has always been the bedrock in the African American family" (8).

There is a strong preference ... in the African American culture to help a person remain at home ... no matter what. It is a very strong feeling ... that the care provided by the family is going to be better and [that] the person prefers to stay at home (11).

The family ties are conceived of broadly, staff members observe that children raised by other family members (aunts and uncles, or grandparents) often become their caregivers in old age and refer to them as Mom and Dad (14). Thus the familial titles in Black/African-American communities may not relate to the stereotypical blood relationship and staff needs to be mindful

not to jump to conclusions. Additionally, family ties often extend into the community. In urban areas where “direct” family may not be living near, one provider finds that there will be “a neighbor, or friend, a church member, someone who is taking an interest in helping them” (11).

In spite of the extensive family network within the Black/African-American community, there still appears to be one primary caregiver. A northern, urban provider laments,

... a lot of my participants have large families. They have a number of children. They have sisters and brothers who are still alive, and on the majority of the cases, there is only one person that is caring for this person. There is only one primary caregiver. There are other siblings or [family] members who are ... basically on the outside looking in (26).

Ironically, in a southern rural area, the demonstration staff has come to the same conclusion despite increased involvement of family members.

If there is a senior or elderly person that is sick, the whole family takes turns taking care of that person. ... The siblings continue to go off to work and they tend to be there at night, but during the day, the sole responsibility would still be on the wife or ... designated child (35).

Furthermore, extended family can mean conflicting care needs.

Many times there are multi-generations living in a household, so they're not only taking care of someone who has dementia, but they're also providing for children who are in school, or providing for other relatives who have few resources of their own (39).

Thus, having more family members in close proximity can mean more assistance and support, but often means less support and multiple care needs to be filled.

Another aspect of family care is the perception of self-sufficiency. A provider who serves Black/African-American clients explains, “the people in this rural area have a tendency to do for themselves and not really reach out to others. ... They take care of their own ... [and] that probably keeps a lot of them from turning to us for help that is available” (14). Another rural provider of services to Black/African-American families agrees, “for some people it's very ingrained in them that you just don't reach out for help ... you do it yourself” (37). This is also found in urban settings. A northern provider further explains,

We [African-Americans] don't like to admit that we have faltered. It's like you don't want to admit that ... you actually need help because you feel like you're looked down upon if you are not able to handle things on your own (26).

The preference for family care also relates to a distrust of non-family and formal services in Black/African-American communities. There are “a lot of non-trust issues which I feel is (sic)

cultural” explains one provider (37). “I think it has a lot to do with ... being African-American, living in more isolated communities where they’ve relied on each other [due to] past injustices,” a staff member observes,

... also sort of a general mistrust of the medical system, and that’s because of not understanding and sometimes lack of education. And sometimes, health professionals not respecting their own methods of taking care of their family ... (39).

The mistrust of doctors and medical services is contradictory in the experience of a northern, urban provider. She finds that many elderly individuals will not seek a doctor’s care “because they don’t trust them” (26). However, she continues, “if they *do* go to doctors, they tend to take the doctor’s word as God’s word. It’s almost like golden. And it’s not to be questioned” (26). Other times, she has seen the use of “home remedies ... goose grease, all kinds of things” (26) in an effort to take care of their own.

This distrust also extends to the government. Many providers have to distinguish the services that they provide from “government programs”.

They think the government’s going to come in and take their property ... There’s a misconception about the whole system. We’ve had to work with that. Sometimes they’ll think we are part of the government just because we’ve had some federal and state funds, and so we have to try our best to try to explain to them that we’re not connected with that, we’re not going to come take anything away from them (37).

This general distrust of formal care services could also be the result of limited funds as well as education. In some cases “it was strictly knowledge; they didn’t know what was available, or how to access it in the community” (39). Other times, the issue is limited financial resources (11). One provider discusses the disparity in her service area,

Here we’ve got very upscale suburban neighborhoods with wealthy people, and then five or ten miles away...you have people without electricity, who really don’t understand what’s going on (37).

Another aspect of limited resources is reflected in the number of caregivers that work outside the home. There is a greater prevalence of adult child caregivers in the Black/African-American communities (Montgomery et al., 1997). And “most cannot afford to quit their jobs” (8). “There are so many households that the caregiver has to also work as well as take care of the client or loved one with the disease” (16). The providers find that these working caregivers are often the most receptive to using services and the least apprehensive about using formal help,

... because they need these things. They are adult children and they're trying to work. They're trying to take care of their children. ... They are less suspicious of people coming in to try to help them (26).

Another issue that providers mention as important in serving Black/African-Americans is the need to be respectful, as respect is something this community has been denied in the past. A staff member observed, "I think that some of these people are still living in the 19<sup>th</sup> century ... there were the owners who had the money and there were the workers who worked in the fields. That was that" (14). One client explained it this way to a provider,

And she says, "We [African-Americans] were not respected in the community at large, and so we absolutely had to respect each other within our homes, and within our churches." And that really was a tremendous insight to me, because that's what you see many times is mutual respect (39).

The expression of respect is important for providers to address. Something as simple as using titles can make a difference. "I call them [my clients] Mr. or Miss out of respect. You owe them that" (17). A staff member warns against using first names without permission, "because you have almost been disrespectful to them by not calling them Mrs. Sara Jones or Ms. Jones" (8). Using titles in the Black/African-American community is symbolic of a broader form of respect as one provider explains,

[During] slavery no one ever had titles. And you have to realize, if you're dealing with someone with Alzheimer's, they're in their '70's and '80's most of them, and these people have never had titles. They've always been Mary ... because they were brought up by slave parents ... like my grandmother was a slave and ... her name was Mary, but I knew him [the white master] as Mr. Smith and that's what everybody called him, even though my grandmother and he were the same age and she was there when he was little. ... So you have a lot of people that had grandmothers that were brought up in slavery or came when there wasn't slavery ... but were still living on property that was owned by someone that was white, and so they never had a title (17).

As this discussion illustrates, such symbolic demonstrations of respect may be extremely important to family caregivers, especially adult children, in entrusting the care of their parents or grandparents to formal providers.

Providers also mention the importance of church membership and the spiritual community in Black/African-American populations. "Most of their [African-Americans] social life was pretty much surrounded around church activities" one staff member tells us (40). "The church is one of the major supports for the African American community" another provider adds (26). "I see faith as a core issue" one staff member clarifies, "[it has a] positive influence on allowing deviant

behaviors to be tolerated” (39). This acceptance can be applied to the behavioral symptoms of Alzheimer’s disease as well as to acceptance of the role of caregiver. A provider explains further, “Whether it’s their beliefs or whether it’s their cultural background—probably in some cases it is sort of like ‘We’re going to accept this’” (37). There is recognition “that this is a child of God and a basic person to be respected regardless” (39).

The ability to care as well as accept is attributed to individual faith or spiritual beliefs.

In the African American community, especially those that I serve, faith is a big part. I believe that faith is what keeps the family itself strong, and I believe that they pull from their faith, especially to deal with types of diseases like this (16).

These are people who are highly religious. They have some type of spiritual guidance in their lives ... spirituality plays a large role in our caregivers’ lives. A lot of them believe there is a possibility that things will get better. That someone can come out of this [Alzheimer’s disease] ... So even though we tell them, there’s still hope (26).

Another staff member describes the importance of personal spirituality,

It gives them a firm foundation for hope. They have a faith that they have learned. Some things they’ve learned to accept as they are and to be grateful for what they do have, and the focus of their devotion has basically been that they thanked the Lord for another day. So each day is one more chance. ... It is their faith that gives them that encouragement to keep on, and that’s an intricate part of their daily life, to give thanks for the life that they have (38).

Religion and spirituality appear to play a key role in the Black/African-American community and may be related to the low reports of caregiving burden and stress (see Study One: Table 8).

A surprising concern of providers targeting services to southern Black/African-American communities was the importance of understanding diet and nutritionally related health issues. “A lot of African-Americans in the south are eating greasy, salty food, and that really complicates the high blood pressure and the diabetes” (39). Another warns, “We have to be very much concerned about dietary factors,” and she advocates, “to move away from the traditional southern cooking” (38).

Providers who serve Black/African-American clients make several generalizations about the individuals that they serve. They perceive a strong sense of family and community ties, which includes the extended family. This has created a greater prevalence of caregivers who are more distant relatives in the Black/African-American community, and involvement by more family members in caregiving. However, it is still most common that one person bears primary responsibility for caregiving, and simply receives input from others. Spirituality and organized

religion also have important roles, both to the Black/African-American community in general, and as support structures for caregivers.

Black/African-Americans, like their rural White peers, possess great pride in their ability to remain self-sufficient and “take care of their own”. A related idea is the pervasive mistrust of government assistance and the medical system. In order to remain independent in the face of limited financial resources, many Black/African-American caregivers continue to work while providing care. The concept of respect among community members is also highly valued, due to past injustices.

### **Earning their Crown in Heaven—Hispanic/Latino Americans**

The more I suffer, the more I’m going to earn in heaven. ... Suffering in silence because this is ... my duty. I’m supposed to do this. It is expected of me and therefore I’m a better Catholic, a better person. ... [I’m] earning my crown in heaven (5).

The Hispanic/Latino demonstration clients included in this study are those in East Los Angeles, California, the Little Havana area of Miami, Florida, and those in Seattle, Washington and the surrounding rural areas. In East Los Angeles, the population is predominately from Mexico and other Central and South American countries. Many are recent immigrants while others are second- and third-generation. East Los Angeles is a Spanish-speaking enclave in the heart of an urban center. The street signs are all in Spanish and all business can be conducted in Spanish—individuals can live in the community and have no need to learn or speak the English language. Little Havana, in Miami, Florida is similarly accessible in Spanish. Many residents do not speak English. The majority of Little Havana’s population came from Cuba in the early years of the Castro regime and are first- or second-generation immigrants. Recently, however, other Central American individuals are coming to Little Havana. In Washington, the Hispanic population is mostly comprised of migrant farm workers from Mexico and other Central and South American countries or their first- or second-generation descendants.

As one provider reminds us, “when we use the term Latino or Hispanic, we’re talking about people from over twenty different Spanish-speaking countries who have a great amount of differences and experiences” (5). “So we really have had to be tuned in to ... how we should approach people a little differently from the different countries—even though they might speak the same language,” another adds (43). Furthermore, the Spanish language is not spoken the same in each country (48). Different words have different meanings among the Spanish

speaking cultures. For example, the word *tortilla* in Mexico refers to the corn *tortilla* that we have come familiar within the United States, whereas in El Salvador it refers to a sweet cake and in Spain *tortillas* are open-faced omelets. The variety of cultures and the variance in the language adds complexity to addressing the language barrier.

Communication issues have been the most acknowledged barrier to serving Hispanic/Latino populations. It is not enough for staff members to be bilingual--they need to be bicultural. Bicultural knowledge reflects the need for an awareness of the larger cultural protocols beyond language and word usage. For example, cultures have what can be called "speaking protocols" that refer rules about who can speak to whom and how.

The communication is different—where in [North] American we tend to lay everything right out on the table and be very frank about things. Especially our health care. The Spanish speaking population is embarrassed by that frankness. You wouldn't sit down with them and out of the blue ask them a ton of questions about their health (44).

This protocol has relevance for how providers discuss client needs and accomplish service intake forms. "If they don't know you," a staff member explains, "They're not going to tell you anything" (45). For this population, communication is predicated upon trust and confidence building (45).

So it's really important for them to see the face behind the name ... it's important for them to see that you care because if not, they will not use your services, they will not feel comfortable using your services, they will not see a need for your services (5).

Another provider adds that, "if you want to establish a rapport with someone, you will have to divulge some personal information" (1). "They'll want to know about your background," she continues, " ... Are you married? Are you not? Do you have kids? Do you not? And do you live alone? ... I think that's important to them because they need to feel that they know you" (1).

One staff member offers an example of a successful intake process.

What it really took was a person from the community ... to bridge the gap. It was just a real different approach from what we normally use when someone ... would come to find out information. We'd sit down and talk about the program and what we have to offer. ... [For] most of our Hispanic or Latino families, the way we would do intakes would be to go to them, sit in their kitchen with them, and talk to them about what we do, maybe have coffee with them, and then maybe come back again and talk to them. And then at that point ask them, "Would you be willing to come over and try having lunch with us one day?" There's a whole different process (50).

Another communication issue concerns showing respect. Speaking protocols for respectful communication between genders, generations, or providers and clients need to be acknowledged. One provider shared the story of her grandfather's expectations,

When you come up to a Hispanic elder and you cross your arms, it's not out of disrespect. I remember we used to have to do that. We would come up to my grandfather to speak with him, and we could not just hang our arms down at the side. He expected us to show him respect by crossing our arms (45).

The format of communication is also an issue to consider. Within the Hispanic/ Latino populations, there is a high rate of illiteracy, especially with the elders (1, 43). This means that written information, newspaper announcements, or mailings may not be very effective formats with a large segment of this group (5). These individuals rely more heavily on the "human relationship" in making decisions about services (43). They want to have a sense that they know the staff member or outreach worker; families want to know that they *care* and they will *take care* of their relative (43).

The fact that many of the Hispanic/Latino individuals served by this demonstration project live in Spanish speaking enclaves further isolates them from mainstream information and services. "The language barrier has made them more isolated" (44). Recent immigrants are "...thrown in a four wall apartment. Nobody to speak their language. No friends. Everybody looks at you ... suspicious" (48). "They need interpreters" to interact with the broader English speaking community (49). Alzheimer's disease issues further complicate this, "The doctors did not speak Spanish and they didn't have all of their needs communicated" (3). Consequently, families seldom know that they have a right to ask for a referral to a specialist.

As with other immigrant groups, Hispanic/Latinos have a tendency to idealize the way things are done in their home countries or in the old days. One staff member tells us, "They don't have the family support that we had in our country" (13). Another adds, "The older people in Latin America care for our children—they're cooking all day" (49). There is a belief that all care needs were taken care of within the family.

Family is the base of society ... The family should provide each of the members all of their needs. ... Families traditionally cared very much for their elderly (24).

We have a very extended family since we are growing up. We have ... the Godfather and the Godmother and you know *compadres*, God's brother and *comadres*, God's sister. You have the grandfather, the grandmother, the uncles, the second uncles, the

third generation of uncles, ... the cousins, the older cousins, the baby cousins. ... It's a beautiful extended family. People that care about you (48).

These idealized ways are still the foundation of current expectations for family care even though their lives may be very different in the United States.

Many of these Hispanic/Latino individuals immigrated due to turmoil and political problems in their home country. This may seem at odds with the idealized notions of days past, yet it similarly results in a preference for family care.

They come from countries where their political entities and government units are very restrictive, so they're not very trusting of services in general, and they don't seek help from government agencies ... They're very likely to just care for their own because of fear (7).

After immigration, most family members work to assist the family (13, 45). Thus, with all potential caregivers working outside the home, there is no one available to provide all the informal care recalled in their previous countries. Often, working parents will assist their mother's emigration to have someone to help with the children. This situation reinforces the mother's isolation from community. "She came to follow one or two of her children and all her extended family remains back home [with] all her friends" (48). This ensures that there will be fewer caregivers available when the mother ages and needs care. Support and care can happen,

... but is harder and harder, and as people's lifestyles change, you have people going off to school after graduation, and there's not the concept of get out of school and stay home with a parent. ... So all of those things impact, and if that person has just arrived a year ago, it's going to be different (45).

These changes in lifestyle have not altered the cultural expectations for family care.

Hispanic/Latino families prefer to "keep things within the home" (1). They believe that family care needs are their responsibility—their job and they do not want to impose on others (1).

There is also a sense of pride.

Pride that I can take care of my own—that I don't have to go out there and ask anyone because I am responsible and ... this is my duty as a daughter, as a wife, as a husband (4).

Most often it is a wife or daughter that is the primary caregiver. "They assume, this is my duty [and] ... it would reflect poorly on me if I seek help" (5). Additionally, familial care keeps the behavioral issues of dementia private.

In the Hispanic/Latino groups served by the demonstration grant, multigenerational family households were not uncommon (3). In spite of this, there is generally one primary caregiver (7) and it's usually female—a wife, daughter, or daughter-in-law (3). “Very, very few families will join forces and be a cooperative effort to care for a loved one” (3).

What I found in this population was that nobody would help [the primary caregiver] but when it came to make a big decision, they would step in and say, no you can't do this, no you can't do that. No, we don't want mama to go to a day care center. No, leave her with the same doctor. ... They wouldn't help but when it came to making the decision, they would step and try to stop them (4).

Another cultural issue of import in Hispanic/Latino culture is religion. As mentioned above, suffering is equated with heavenly rewards. Thus asking for help would be giving up celestial bounty. In contrast, “There's a very strong belief in fatalism in that religion [Catholicism],” one provider explains, “You know, what have we done, what has this person done to deserve this” (5)? This inference of bad behavior or blame reinforces the preference for family care to avoid social stigma. “A lot of families were ashamed to admit that their loved ones had dementia, and/or because of their cultural belief system, it was something that was shunned” (7).

The degree of religiosity also leads to use of alternative medicines as one provider explains,

There are many alternative Latino beliefs in medicine. For example, *cura medicimo*, a belief in shamans or for lack of a better term, witchdoctors. ...But alternative herbal medicines can cure the problem, spiritual leaders that can cure the problem, a high belief in religiosity and faith and how that influences things (5).

Another staff member correlates the use of alternative means with lack of resources as well as beliefs.

A lot of the family members were really adamant about [not] taking their parents to be diagnosed because of the cost and/or they didn't have access to transportation, or language variances. And yet ... they would take them to folk healers and they would pay tons of money, because they folks would promise them an instant cure. For example, if you give them this sort of tonic or if you do this ritual three times a day, your person will be cleared of their possession. It was very interesting to try to see how the myths, the folklore, the traditional cultural belief systems were more dominant than their belief in the traditional Western medical care (7).

Several general characteristics of the demonstration's Hispanic/Latino clients can be identified. The term “Hispanic/Latino” represents a great diversity in cultures, dialects, and etiquette. Gestures of respect are considered important, and differ by group within the culture. Many clients are monolingual Spanish-speakers with relatively low levels of literacy, which results in

isolation from mainstream services, and a greater valuation of one-on-one relationships with service providers.

Despite the diversity in cultural norms within the Hispanic/Latino community, each nationality displays a very strong reliance on the family unit to solve problems and provide care. Immigrants bring with them traditional expectations for family care.

### **Ethnic and Geographic Diversity**

Though all families were confronted by the common needs in caring for someone with Alzheimer's disease, each cultural population had its own history and understanding of how care was to take place. Rural families stressed self-sufficiency and were isolated with fewer opportunities for information, services, and other resources. Black/African-American families were accepting of the care needs, had strong extended family ties, and supportive church community ties. Hispanic/Latino families conceptualized caretaking as a spiritual matter and faced the most communication barriers.

These families shared the desire to provide care within the family. Providers also mentioned that showing respect was an important component of serving both Black/African-Americans and Hispanic/Latinos.

### **RESEARCH QUESTION #2: WHAT IS THE PREVALENT VIEW OF ALZHEIMER'S DISEASE IN THE TARGET POPULATION?**

Providers report that there is an increased general awareness of Alzheimer's disease within the general populous. "Folks are hearing more about it [Alzheimer's disease] on public spots—President Reagan's disease and so on" (21). A staff member adds, "Alzheimer's has certainly been out there in the media and there's so much in the news about it now that I think times have changed and the perspective has changed in recent years, just in the past two or three years" (22). Another elaborates,

I think people know about what it [Alzheimer's disease] is, just because ... there's been a lot of movies and articles and things. I think maybe they tend to think the worst--that all people with Alzheimer's wander, or all of them are violent. But I think most people are aware of Alzheimer's. I don't think they know exactly what it is and how it works, but they are aware of it (23).

"Everybody I've talked to, the family caregivers at least, have heard of it," a case manager said, though "they cannot conceptually understand it" (11). An administrator explains, "The average view ... is that it is a terrible, devastating disease, in which the person is totally not themselves (sic) and is going to do terrible things and have an awful death" (39).

### **Shared Beliefs**

Even though there is an awareness of Alzheimer's as a disease, misconceptions about the symptoms persist. Many of these notions were common across cultural groups.

#### ***Alzheimer's Disease as Mental Illness***

Many individuals still believe that Alzheimer's disease is a form of mental illness with the attendant social stigmas. The terms "crazy" and "insane" are mentioned frequently to describe individuals with Alzheimer's disease.

...People are going to look at her or him as insane—that they're crazy and they use the word a lot. ... They equated it with a mental illness (4).

... Alzheimer's disease means that they're crazy and they've lost their mind. You hide it ... whoever had it; they [the family] hid them at home. They were embarrassed, like "that's mental health—that person's crazy" (17).

... some of them in these real rural island areas actually lock that person up in a room and call them "crazy head" because they don't understand the disease (37).

They just ... don't want to talk about Alzheimer's disease because, ... someone may think that I have crazy people in my family (8).

Though found in all the demonstration populations studied, this is perhaps most pronounced in the Hispanic/Latino communities. Hispanic/Latino populations "consider that [Alzheimer's disease] being crazy, and that's like a blot on their family" one provider explains (15). Another mentions that Alzheimer's disease is seen as "a weakness in the family" (42). "The word dementia in Spanish means crazy," a staff member explains, "Not in the dictionary, but for the people, it means crazy" (24).

#### ***Normal Aging Process***

Frequently, providers mentioned the prevalence of the belief that memory loss is part of the normal aging process. One staff member illustrates a client's belief by noting ... "My mother

has memory loss because this is normal for an older person to get to lose their memory". Furthermore, another provider states that caregivers often do not look for services or assistance in the early stages because "they assume that whatever is happening is part of normal aging and not a disease—they think that memory loss and these behavior problems are something that just happens" (5). In the rural areas, some local physicians further this misconception. One provider says, "[Doctors] can hardly say the word [Alzheimer's] much less diagnose it" (31). She offers a story of a client whose doctor said, "Yes, she is forgetful but it is not unusual for a woman her age" (31). Another rural service provider paraphrases the local physician in her community, "The doctor will laugh it off and say, 'Well what do you expect, you're getting older!'" (21).

### ***Family Denial***

Believing that dementia symptoms are part of normal aging facilitates family denial with regard to Alzheimer's disease. Providers mention family denial as a challenge that they face in the three populations included in this study. One staff member paraphrases her clients,

We will not admit and that is the problem. It could be like shame, you know. Why? How? It's not possible that people are going to find out that Mom is behaving this way. This is not normal and it should be kept in the family (48).

Family denial can take many forms. Some are reluctant to use the "A-word".

I've had a number of families tell me, "Please ... when you come out to our home do not say the A-word." It's like a ... curse word almost. "Don't say it in front of my mother. I don't want her to hear that word" (11).

... it's that word. Nobody wants to use that word. I mean I've been told a zillion times ... "Oh, she has dementia, she doesn't have Alzheimer's" and you know, it's just that word itself, and it's okay to be forgetful but not to say that she has Alzheimer's (31).

Others believe that their relative is "just acting like they don't understand" (47) or its "a misbehavior or something that the person could control if they wanted to" (42). Families "want that person to be what they used to be, and they're not" (17). According to a few staff members, the likelihood of denial varies among family members with different educational levels. "The more educated the caregiver, the more denial they have" (17) one says. Another explains, "The ones that were more educated, it bothered them more so when their loved one was acting out in a way that was not appropriate" (30).

Denial further complicates things, as family members may not acknowledge the symptoms and behaviors associated with Alzheimer's disease.

A lot of times they're in complete denial that there's anything wrong. ... Sometimes I'll go out and they'll say "Sometimes they're a little bit forgetful, but they're fine." And then I go out and do an assessment, and I'm like, "Oh my gosh, they're not safe." There's a lot of dynamics in that because it could be that they're really good at covering up (28).

The need to save face or cover up tends to be more of an issue with spouse caregivers, especially wives.

I find more with female caregivers that they will not tell me what the husband is doing, if it's a husband-wife situation, all the things that are going on because I think that she might be trying to save face for him. The children are more apt to come right out and say, "Mom or Dad's doing this," but spouses tend not to do that (27).

Sometimes caregivers still hold out hope that things will get better somehow. This form of denial may be deeply rooted in religious or other beliefs. Many clients "still have that faith that there is a possibility that things may turn around" (26).

... even though she had read up on Alzheimer's, her thing was that her husband was going to get better. ... She read up all this information about how different types of vitamins would help stimulate your memory... and she was adamant about giving him his vitamins every day (10).

The fluidity of Alzheimer's disease symptoms can facilitate this belief. One provider shared her experiences,

There are some caregivers that just say, "She has her good days, and she has her bad days." But really through faith they're praying and hoping that it will get better, or it will just leave, or some type of miracle will take place (16).

Other times "caregivers sometimes feel that if they could just do a better job of caregiving, that this would be getting better sooner ... many folks have self doubts, as 'maybe I shouldn't have done this' or 'I wonder if that caused it?'" (21). Worse may be the times when family members blame the caregiver for the individual's symptoms.

[Caregivers] understand what is happening but you have siblings, you have grandchildren, you have brothers and sisters of these clients, [and] ... they don't understand what is happening. They blame the caregiver. "It's your fault Mom's crazy. It's your fault she forgets things. ... There is a denial because they don't understand the illness (3).

Family denial often leads to higher stress levels. "When they [caregivers] come in denial and deny that their loved one has Alzheimer's, they're usually stressed out" (10). It can also be the difficulty in coping with behavioral problems that make no sense (3) that contribute to the caregiver stress levels. Families may be reticent to seek a formal diagnosis as "they don't want to confirm the reality of the problem" (47). But providers see relief in a diagnosis that makes

sense of the odd behaviors for the individuals as well as the families. "I think once they're told, there is some relief, like, 'Oh my god, I'm not losing my mind'" (28). Another provider paraphrases her clients, "I thought I was going crazy and I'm almost relieved to know that I'm not—I'm not happy having Alzheimer's but at least I'm relieved to know I'm not crazy" (21).

I think people really want to know ... as opposed to wondering what it is. They know something is wrong, and putting a name on it that they're familiar with ... isn't too much. But some of the behavior, if its inappropriate or exposing themselves or doing things like that, I think is a problem, but not the disease itself (23).

### ***Embarrassment and Fear***

Most families are "fearful of Alzheimer's disease ... they just don't know what to expect" (14). This fear has several aspects. Some are afraid of having Alzheimer's disease and worry that it could be contagious. They worry that they might get it (35). Others are afraid that their relative "is not going to recognize them" (47), while other families express fear of embarrassment caused by some of the behavioral symptoms of the disease (47). For others, it's the stigma that Alzheimer's disease is a sign of previous bad deeds.

Some people think it's an embarrassment. Folks will say ... he must have done something then to have caused it (21).

Some families fear burdening others with their private issues and are uncomfortable taking their relative with Alzheimer's disease out into the community. Many caregivers don't want "to visit other people and burden them if the person has any type of behavior problems—they'd just rather stay home and not go out" (1). A large number of families prefer not to let anyone know that their relative has Alzheimer's disease (32, 13). "It's an embarrassment for the family...so please don't let anyone know," one staff member explains, "because people will look at you as that [your] whole family is crazy" (30). Families "try to keep it private and conceal the disease" (16). Others are "afraid that people will think that they have Alzheimer's" too (2). Families may be reacting to general societal beliefs that Alzheimer's disease is "something really, really bad" that they "don't want to get near" (3).

... they're afraid. Sort of like, "not in my backyard," if you will. "It's most unfortunate that Mr. So-and-so has Alzheimer's and I want the best for him, but I really would rather not be his next-door neighbor, because that may mean that I'll have some awkward moments, or I'll have to be concerned about him, or those kinds of things" (22).

### **Cultural Views of Alzheimer's Disease**

Providers from all three cultural groups under study mentioned the belief that Alzheimer's disease is a mental illness, or a part of normal aging among the communities they serve. Family responses of denial, fear and embarrassment were also not limited to specific ethnic populations. However, among this commonality, there were some comments that were particular to individual groups.

#### ***Rural Communities***

Demonstration providers explain that there is a lack of general knowledge and understanding of Alzheimer's disease in rural areas. Most families are dependent upon their family doctors for dementia information (28, 20) as there are fewer resources in rural communities. Though some staff members mentioned local physicians that were Alzheimer's aware, more noted the lack of awareness in their community doctors (31, 20). This lack of knowledge and informational resources leaves families with little understanding of the disease and the disease process (30, 36).

The other perspective that is relatively unique to rural communities is the likelihood that residents tend to know a lot about each other's lives. For example, one provider explains,

Chances are that if you are a long-standing member of the community, you're related to everybody in the community. And if you do something inappropriate in public, chances are about the [whole] town will know about it by the end of the night (27).

This lack of privacy enhances the social stigma of Alzheimer's disease behavioral symptoms and makes family denial and face saving much more difficult.

#### ***Black/African-American Communities***

In Black/African-American communities, providers note that Alzheimer's disease is more accepted. "People here tend to be more realistic—this is it—this is life" explains a staff member (14). One administrator adds that Black/African-Americans "would not conceal ... the disease, and would accept help more readily" (39). Another provider observes that this acceptance leads to "tremendous family responses" (43). She relayed a story of one family,

They completely reorganized their life in order to do the care ... We watched a young woman who has three teenage kids and her mother has got severe dementia and she sees humor in it. I've noticed that a lot in the African American community. There is some acceptance and ability to laugh and then a strong commitment to caregiving (43).

### ***Hispanic/Latino Communities***

Some Hispanic/Latino families place their understandings of Alzheimer's disease in the spiritual realm. They often believe that caring for a relative is just "their cross to bear" (5). Hispanic/Latino communities have folk beliefs about Alzheimer's disease and its cause. "Some people do see it as they've been cursed [or] they have done something bad in their life span" (5). Other times, people may believe that they are "being possessed with spirits, or all kinds of different religious explanations" for the dementia (46). A staff member notes that these beliefs are more likely to be seen in less educated, first generation immigrant families (46).

Believing in curses, punishment, and possession leads individuals to seek non-medical cures.

If you believe the illness is because of some physical dysfunction in your body, then you are going to see a doctor. But if you believe the illness is caused by the witch next door that covets your husband then that's something from the spiritual realm (5).

Providers also spoke of families going to *curanderos* who act as shaman and can dispel curses (5).

### **Views of Alzheimer's Disease**

Among the cultural groups included in this study, there was more commonality in approaches and responses to Alzheimer's disease than differences. The belief that Alzheimer's disease is a mental illness or a part of normal aging was shared across cultures, as were family responses of denial, fear and embarrassment. Rural communities were unique in the lack of information readily available and were more likely to be part of a community where privacy was at a minimum. Black/African-American populations were seen as more accepting and realistic in their approach to caring for a family member with Alzheimer's disease. And Hispanic/Latino families often viewed Alzheimer's disease in spiritual or religious terms.

### **RESEARCH QUESTION #3: WHAT IS THE PREVALENT VIEW OF USING SUPPORT SERVICES IN THE TARGET POPULATION?**

There are several common beliefs about support services and their use that are shared by the three cultural groups included in this study. There seems to be a widespread lack of understanding and awareness of just what "respite services" are and how they are used. As one provider explained, "If I say the term respite, nine times out of ten people don't know what respite means" (8). Another provider adds,

... a lot of times people don't understand what our purpose is—what home respite is. So, ... that was a challenge in the beginning, to get people to realize what respite is (26).

### **Shared Views of Support Services**

#### ***Confusion About What Respite is***

Often, caregivers will call dementia information phone lines with little expectation that services might exist. "We get phone calls from people saying, 'I was told to call; I have no idea what you can help me with'" (8). Even though the general public awareness of Alzheimer's disease may have increased, most individuals are still quite unaware that dementia-specific services exist (16; 3).

Most people are not aware of support services. And I think that's across the board, across all cultures. ...It is not something you think about everyday. ... In general, the whole system of service delivery for older adults is completely fragmented. So if you receive home delivered meals, you might not know that older adults are also eligible for transportation, unless you're a social worker. Most people don't have the slightest idea what services are out there in the community (5).

This lack of understanding seems to be more pronounced with day care services than in-home respite. The concept of day care for adults is a "relatively new service and people just don't realize there is a possibility of having adult day care" (42). Families are "reluctant at first ... they're not familiar about what it [DC] is" (1). "People don't understand it [DC]—they don't understand the benefits somebody can have from it" (21).

In-home respite may seem more familiar as families are often aware of home health services, or in some cases domestic workers or maids. Confusions around in-home respite more often revolve around the role of the aides while in the house. "A lot of times they consider them maids and not ... [respite] aides. We have a constant battle with that. They think they're out there sometimes just to do housecleaning" (35). For many families, it is difficult to have a stranger come into their home,

... and usually when they accept the service, they're thinking that they're getting a homemaker, in other words, a maid ... that is going to go there and clean and cook. Where really, the in-home service [at this agency] is companionship, it's like a social visit ... Of course, they do some help ... but they're not a maid ... and usually what they want is a maid, and sometimes there's a conflict. It's a very touchy thing (15).

Families find it easier to relinquish the household tasks to "strangers" than the care of their relative.

In other cases, families' sense of dementia stigma or denial will keep them from using dementia-specific services but they will use home health or other non-stigmatizing services. "I don't know what the stigma is, but they're just hesitant to come out and use the services" says one provider (34). Another staff member relayed the story of a family that would bring their mother to the senior center for an exercise class, but refuses to use the day care offered there. "The family refuses to bring her because to be involved in this group, everybody knows that you have memory loss" (31). Other times, providers come up against families that hire domestics to care for their elder.

... with the white community up there in the rural section, they have hired housekeepers and people that come in and sit during the day and take care of their person. They are not trained, they are merely maids or domestics, pretty much. But that's the way they've always done it, and they don't see any reason to change it. They don't seem to understand ... that there is value to respite services for the person that has the disease as well as value to the caregiver (40).

This confusion between the roles of domestic workers and respite aides points to the broader issue of value. Because the disease is seen as hopeless, inevitable decline, many do not comprehend that dementia-specific services can make a difference for the individual.

### ***The Value of Dementia-Specific Services***

Once an individual is diagnosed with Alzheimer's disease, general deterioration is thought to be unavoidable. This thinking facilitates an acceptance of whatever decline occurs rather than working to maintain as much as possible for as long as possible. As one provider explains,

A lot of times people are surprised that we are dementia specific. ... That we do activities that are specifically geared to try to allow people to maintain where they are as long as possible. ... So there is surprise at what we do. And they [family] are surprised, "Well, she won't do this at home ... how'd you all get her to do this?" ... Because a lot of times people get the diagnosis of Alzheimer's disease, people will assume that they no longer can do anything. And they don't give them the opportunity to be who they are (26).

Another staff member adds that she tries to, "emphasize on how important it is if you keep them socially stimulated. Stimulation," she continues, "keeps it [the deterioration] at a certain level for a while" (4). Families often don't realize this possibility. Additionally, when families believe that their relative's symptomatic behavior is "just part of normal aging," they are less likely to seek services. These families do not see any value in support services as they also see decline as inevitable (11).

### ***Family Care is Better Care***

Families often believe that, because of their emotional attachment, no one else can care for their relative as well as they can. One provider refers to this as, “letting go” (3). She explains that families have difficulty “letting go—letting someone else take care of their loved one—[it means that they are] admitting that they need help” (3). Another provider concurs; families believe,

that they actually can do it better, that nobody else is going to really take care of their person, really see them as an individual like they do. And so they are reluctant to use [respite], because they don't think that their family member will be respected for who they are” (39).

Only the person that's closest to them,” she continues, “can give them the emotional support on an on-going basis” (39). Providers are left with the task of assuring clients “that we're going to be able to give the kind of care that they want us to give” (50).

Another provider believes that there can be co-dependency in caregiving that deepens and complicates the issues surrounding service use. She sees that these caregivers are often reluctant to use services, even though they may be clearly overwhelmed, because their identity is tied to caregiving, being needed, and being the relative's only support.

I even have support group meetings on ... co-dependency... They'll say, “I'm so tired. This is not what I planned on doing, it was supposed to be a family thing. Everyone's supposed to share it. Everybody's supposed to do it.” And I just stop her and say, “They hold a gun to your head, and make you take all of the responsibility?” I have to get into it further before I can talk with them like that. I say, “Nobody made you do this. You're doing this because you want to do it, so don't blame anybody... If you don't want to do this, put them in a home or let somebody else do it (17).

Thus the decision to let go and share caregiving responsibilities is tied to any possible permutation of family dynamics. Some providers have found that overwhelmed caregivers will often use services in spite of the family dynamics or other considerations. Once they reach a certain point, they welcome the help (8).

Most of the time [we're] getting people at whit's end. They've tried to manage this person at home ... and it's like we're a refuge now. They come here and it's like, “Oh my God, where have you been all my life (9).

### ***Family Guilt***

Much family guilt comes from normative expectations for family caregiving in our society. Families internalize this belief and then members feel guilty when they cannot live up to such expectations. A provider shared a farm wife's story, “[she] will basically totally wear herself out

taking care of the husband because of being proud and thinking she should be all and do all...they feel like they're supposed to do it all ... that's the way they were brought up" (35). Other times, family members have "made commitments to their family members, saying 'I will never...'" (26). This is common for married couples who promised to care for "better or worse". Often they feel that they would be abdicating their responsibilities if they were to let someone else assist with the care needs (31).

Using support services, in these cases, is a confession that the caregiver cannot meet the care expectations. It means, "they have to admit that they can't do it, and that's hard for them to do" (31). Families struggle with the guilt of not meeting their expectations. "Just admitting that they can't handle it themselves is a tremendous hurdle" that must be met before they will consider using services (22). Using services also can mean a loss of independence for the caregiving spouse (23). In other cases, caregivers will use the service and continue to feel guilty. A provider mentioned the story of one family using services where the caregiver was "the guilty daughter who is working full time and they can afford it, but they just feel bad about it" (46).

Another component of family guilt is found among those who are concerned about using too much of the service. One provider mentioned that some of her clients, "felt that they were taking money away from someone else that might need it more than they did" (40). Other families will use the social programs, but not the personal care services, as "they prefer to keep the more intimate care in the family" (44). There are others, however, "will just go with a minimal amount of care rather than having to worry about something else, which to them would be filling out more forms and applications" (22).

### ***Embarrassment***

In some cases, families are embarrassed to look for services because it means admitting the symptomatic behaviors of their relative.

A lot of people are afraid to call and say I need help for my parent because they're forgetting things or I have a wife that forgets things or my husband wanders off and I'm afraid that he's going to get hurt. It is ... an embarrassment to admit that (3).

Caregivers sometimes try to "save face" for their relative and don't want others to know about his or her behavior. A provider mentioned a husband who "didn't want other people to know that she does these things" (31). Sometimes caregivers are even reluctant to let other family members know. "They don't even want the other family members to know what is going on so they don't even look for services... they are ashamed" (13).

Other times, caregivers are afraid that if they tell someone about what they are experiencing, that their relative would be institutionalized against their will.

[If they] know that my loved one has a problem then they are going to come in and they are going to take her. They are going to place her or they are going to ... try to get her into a mental institution because she is not acting the way that society says she should be acting (30).

Sometimes caregivers isolate themselves and their relative,

They don't go to church anymore; they don't go to family functions—Sometimes [caregivers] feel that if these folks were to find out that they were asking for help outside the family unit or their close friends, that person will get hurt (7).

They don't want anyone to know and they don't want to face the family stigma about using services.

### ***Anxiety and Trust***

When families do decide to use services, they can be quite anxious about trusting someone else to care for their relative. "I think that most of them are like a new mother putting her child in daycare for the first time. That is the fear and anxiety that I see when they come in" (9). To overcome this, it's important to develop a sense of trust between clients and staff. "In order for them to feel comfortable with you, they have to trust you" (37). In some cases, the process of trust building can be gradual. One provider shared the story of a husband who accompanied his wife to the day care.

At the beginning, he was going with her every single day until finally, I think it was a matter of trust. He realized that everything was fine. [Then] he started attending another day care once a week by himself ... [and] he started attending the nutrition sites. He ... never did [completely] detach from his wife... He was ... there at least every other day until he died (48).

Family dynamics play a significant role in whether a caregiver will use services and in the process whereby that decision can be made.

### ***Younger Caregivers are more willing to use***

Younger caregivers are more apt to try and seek help. To ask for someone else to come in to give them a break—give them a day off. The older caregivers have that commitment, that obligation. Especially if it is a spouse. They are very protective of their spouse. They don't want anyone to come in and take over (3).

This may be due to their generational cohort or to family relationship. "I see with them [younger caregivers] it's not quite as difficult to convince them that it's okay to get some help in caring for

their parents” (50). One provider speculates that adult child caregivers are more often working full time (11). He goes on to explain that taking care of one’s parent is

... not something that is expected in [the] life processes. ... We understand there is the aging life process ... so when frailty and cognitive impairment happen in old age, we kind of understand that as a life process, but if it happens in your 50s ... it is much more devastating (11).

He believes that younger caregivers’ willingness to use services has more to do with where they are in the life process rather than generational effects. Younger caregivers also make the decision to increase or expand service use more quickly than older caregivers regardless of family relationship. Another provider speculates that willingness to use support services has to do with greater life exposure to a variety of events and places (40). Younger caregivers have often experienced much more diversity in life than their parents. They are also likely to be better educated, and therefore would be more open to trying different approaches to caregiving than would someone older.

Providers also note that adult children or younger caregivers are much more likely to see support groups as useful. Older caregivers are often suspicious of support groups believing that they are only “for alcoholics and drug addicts and stuff like that” (8). Older caregivers “don’t want that kind of help. It’s just not what they’re accustomed to but their children are a little more open to it” (19). Another provider paraphrases her clients,

I think [that to] a lot of my clients that counseling means there’s something wrong with you. There is something mentally wrong with you to go to a caregiver’s support group and I’m not crazy. She’s the one that’s crazy—the person with Alzheimer’s is the one that’s crazy (30).

### **The Welfare or Handout Stigma**

Since respite services are often offered at a low or no cost, some families see these services as welfare or a handout. “That’s such a barrier... people think that [this agency] is for indigents... [and] the unique thing ... is that we serve everybody” (28). The general public “look[s] at any type of help as welfare,” says one provider (30). Another staff member explains that this view is more prevalent among older individuals, “they think of programs as welfare—well I can do it by myself...that sort of thing” (20). In other cases, it may be the privacy about finances that is the hurdle providers face. “They’re very private about their financial status and issues, and [have] some reluctance ... to accept what they may see as welfare” (22). Other times it is just about being seen as a “user”. There is “the stigma of being a user, someone who drains the system

... it is a huge stereotype" (5). Families "just don't want anyone to think that they are trying to get a handout" (30).

[Caregivers]... seem to somehow find that services like this is sort of a welfare program. ... The tag of welfare, we have difficulty [with that]. We're trying to persuade them that this is a service and it's not welfare. We do hit a brick wall with that sometimes. The neighbor may say that even if it's not food stamps or something like that, the neighbor may see the caregiver and sometimes [be] thinking under the welfare tag (35).

A provider explains, "it gets back to ... pride. I'll hear them say, 'I never took a handout in my life!' or 'I worked all my life so I wouldn't have to be on Medicaid'" (28). The notion of handouts and welfare seems to be a pervasive misconception.

In contrast, however, in urban environments with more educated caregivers there is less "welfare" stigma about using services. This may, in part, be related to the fact that urban providers are more likely to charge some sort of fees, even if they may be on a sliding scale.

We have not really had any problem in gaining acceptance for this kind of service. ... I actually feel that people are expecting support services. In fact, they feel that they deserve and want them and are entitled to them and should get them (12).

Another urban staff member has a similar view, "most families are very grateful to receive our services" (11). He continues to explain how support services fill in a gap between the poor and the rich.

If you are very wealthy you can afford to pay privately for home care and if you're poor, you have medical assistance, which will pay for home care services. But if you are in that gray area where you are [in] ... that low to moderate income, you're over the Medicaid eligibility line and you're kind of stuck in the middle. And you need the help but you cannot afford to pay privately so fortunately, because of the funding that we get, we are able to provide services at a reasonable cost (11).

Even though the "funding" that this agency receives is from the federal government, it is not perceived as welfare at the client level. However, it is related to another consideration providers hear from their clients—fear of the government.

### ***Government Help***

There seems to be a general reluctance to accept "help" from the government across the three cultural groups studied. However, this distrust has different explanations in different groups. In Maine, there is a fear that the government will take everything they own.

You need to know the history of the area, [but] ... a lot of individuals... do not want services if they're quote, unquote, government based services and it's been very difficult to alleviate fears. A lot of times in the past when people accepted any service that had

Medicaid attached to it, they would have to pay the money back and people had their land and their house that had leans on them as a result. People still remember that (18).

In other rural areas, it can be an issue of privacy. Families “don’t want to give out private information—they feel like their income or what their assets are are private” (37). In Black/African-American communities, providers believe that it is a lot of distrust and often mention the Tuskegee experiment as an example. “Being African-American, the history of trust is not there... they’ve lost confidence somewhat in the system” (40).

This distrust, seen by providers in Black/African-American families, is also evident in a lack of willingness to participate in research projects as well. “There has been a great deal of reluctance to participate in that [research] program because ... people have a tendency to believe there is still some undertones... there’s still some fears” (26). However, in contrast, providers to Hispanic communities find presenting the demonstration services as a research project is better received than talking about it as a government program.

I won their confidence [by] telling them this is a research study...”Please allow me to help you so that we can learn together. Me by helping you. You by allowing us to understand what you are going through (4).

Fear of the government appears strong within the Hispanic/Latino communities. Many times, this fear comes from families’ experiences with the governments in their country of origin (5). Or it may be that they are in this country illegally (24). Other times, families can be concerned about privacy. A provider in California relayed a story about a man who had been a citizen for many years. He told the provider, “[If] it was a government thing that was going into his business and he didn’t want to tell anybody anything” (4). Additionally, there are some people that just “have a long standing institutional bias against health organizations or other programs because in the past those organizations have not met their needs” (5).

### **Culturally Diverse Views of Support Services**

Though the majority of views about support services are shared among the groups studied here, there were a few issues that only providers to the Hispanic/Latino communities mentioned. This cultural group differed mainly due to issues relating to their immigration. The Hispanic/Latinos served by the demonstration came from a variety of other countries. Most of these countries had little or no support service system.

...especially if you are talking about recent immigrants from other nations. Those countries don't have social support infrastructures at all. So the expectation that there might be something in the community to help you out is not there. Rather, the assumption is, your family's role [is] to take care of that person (5).

Thus, these individuals are less likely to be aware of support services or have any idea what they are, who they are for, and how to access them. Indeed, the culture of their previous country enhances the notion that "the family is to provide for every need of every member and that means that they are a little ashamed or offended if they need to have services from outside the family" (24).

Additionally, because of a family's prior experience with another government regime, they may be especially fearful of all government programs. A provider in Washington state mentioned a client from Columbia that was so fearful he went into hiding with his wife who had dementia (48). Protective services can be reminiscent of individuals who disappeared in their home countries. Of course, if the family or some of their members are in this country illegally, that also complicates serving them as well (24).

The other issue that is germane for Hispanic/Latino populations is that of language. As one provider explains, if they can "read and write in English, it makes it easier for them to get services" (3). Communication is a key component to both understanding what a service is and how to access it.

### **Client Views of Support Services**

For the most part, client views about support services did not vary by cultural grouping. Indeed, most providers found a general lack of understanding of just what "respite" is and a limited appreciation of the value of dementia-specific services among their clientele. Staff members faced the notion that family care is better than professional or paid care because of the emotional component. Families of all cultural groups expressed guilt at using services, embarrassment about the behavior symptoms of Alzheimer's disease, as well as anxiety and trust issues in letting someone else provide care. Providers also reported that younger caregivers, regardless of their family relationship or ethnicity, were more receptive to service use than older caregivers.

Providers mentioned having to address the stigma that support services are a form of welfare or a public handout. However, this was more pronounced among rural and less educated families. There was also a general distrust of the government in rural and ethnic communities. In addition to the above views, agency staff in Hispanic/Latino communities mentioned that their clients' perceptions of support services and government programs had been shaped by their experiences in their countries of origin. These providers also mentioned that the language barrier inhibits their clients' awareness of traditional support services and ability to access them.

#### **RESEARCH QUESTION #4: HOW WILLING ARE MEMBERS OF THE TARGET POPULATION TO RECEIVE SERVICES FROM STAFF OF DIFFERENT BACKGROUNDS?**

In developing services to reach new populations, staffing considerations have been important. Agencies have used workers of backgrounds both similar and dissimilar to their clients. In some cases, racial bias has been a challenge. In rural areas, racial similarity is strongly desired by caregivers. However, familiarity, community membership, religious affiliation and common gender can take precedence over racial similarity at times. In Black/African American communities, there is a prevalent mistrust for White workers that originates from a history of oppression. Hispanic/Latino families desire staff members that are both familiar with the culture and language, as well as cognizant of national diversities. In spite of these challenges, the delivery of quality services, along with the demonstration of respect and caring by providers, can overcome ethnic differences in many caregiving settings.

#### **Rural Areas—The Value of Familiarity**

Providers in rural areas serve a population that is simultaneously uniform and divergent. Although rural residents of varying backgrounds share many of the same influences and barriers due to their relative isolation, they perceive subtle differences between themselves and their peers that may affect their judgements about support services and providers. Providers discuss several elements of "background" that caregivers and elders seemed to include in their evaluation of respite staff members.

#### ***Ethnicity***

As might be expected, providers frequently mention ethnic differences as occasional problem areas for acceptance of staff. Some have dealt with care recipients who were not receptive, and even abusive, to staff members of different ethnicities. A provider remembers,

sending an African-American volunteer into a Caucasian family,...and the patient actually treated the volunteer quite badly...But not in all cases, this has probably happened 10% of the time, but that 10% makes a big impact on you (27).

Racial biases of elders also come into play in a multi-racial day care setting. When care was provided intermittently by both White and Black/African-American staff members, one provider has observed differential treatment of Black/African-American staffers by White clients. "We have heard really negative and terrible language, just calling them names and expecting them to be like the hired help"(28). She attributes this overt bigotry primarily to their up-bringing, and the decline in social inhibitions brought on by dementia. "They're demented, and we're not going to be able to change what has been going on their whole life and how they were raised"(28). In the absence of abusive behavior, elders may find other ways of protesting care by a person of another race. A Black/African-American provider was sometimes amused by White elders' reactions to her:

I had a referral from a family member, and this lady [elder] didn't like African-American people, but her caregiver was not available at the time so her son called here. I went out to do an assessment, and she stayed in the bathroom all the time I was there (29)!

Care recipients are not the only ones for whom ethnicity matters. Members of the elder's immediate family may also be against the idea of their family member interacting with someone of another race. The ethnic composition of care recipients at a particular agency can prevent family members from seeking their services. In regard to her agency, a provider in rural Florida comments that "there are some people, some of the white people in town who wouldn't send their loved one here because of the large population of Black people we have in the day care" (14). Even after the barrier of beginning service is past, family members may not feel comfortable with care that is provided by an ethnically dissimilar staff member. One provider laments, "I have had family members actually comment to me, and the staff, 'I don't want that person touching my husband,' or whatever...It's difficult" (28). According to providers, this reaction to staffers of different ethnicities is not uncommon. A Black/African-American provider going to an in-home assessment of a White elder in a White area of town foresaw this problem and asked a White volunteer to accompany her.

Sure enough, after we got there and introduced ourselves and why we were there and were taking notes, the phone rang and the husband answered the phone. His statement was, 'One is, and one is not.' So my volunteer looked at me, and I looked at her, and we had a big smile (29).

### ***Community Recognition and Similarity***

In rural areas, a unique aspect of staff members' backgrounds is their family background and recognition within the community. The limited size of rural communities often breeds greater familiarity between citizens, as well as their extended families. This can create a greater feeling of comfort with those who are known, in contrast to "outsiders". Thus staff members who are known to the families of care recipients, regardless of ethnicity, are likely to be better received than those who are not.

You can see it and you can hear it in their voice when I call them or if I tell them so-and-so [is coming to provide care], and you get this, 'Phew, I know this person.' Or even if they don't know the person, but if a cousin three times removed was married to a relative of this person or something, it's just like old home week. So it makes a difference (27).

A common response on the part of providers was to preempt possible conflict by sending a staff member from a similar background whenever possible. As one provider says,

I will send somebody else of their race and see if that works. And if that works, then so be it, because we are here to please and to satisfy. We can't change a person's feelings or the way they think. We can only be there to serve them (29).

Thus, providers try to give clients what they expect and what makes them most comfortable, regardless of the biases that drive those expectations. This decision is also motivated in part by desire to protect staff members from entering tense situations. Another provider states frankly, "If we get a referral, and we know by the conversation that they are reluctant to receive, say, a Native American, we don't send that person in there. I will not send my volunteer in there knowing what the situation is" (27).

Several providers mentioned other characteristics of a staff person's background that might influence a client's decision to accept or reject services. The importance of religion to life in a rural area can make a staff person's faith relevant to her acceptance. Elders may also prefer to be served by a staff person of the same gender as themselves due to modesty, "a lot of times these older gentleman, rural country farmers...don't like a woman giving him a bath" (35).

### ***Overriding Value of Care***

In contrast to these problems dealing with staff diversity, some providers in rural areas found that the value of respite to caregivers can outweigh other issues. Once families of care recipients know that services are of high quality, they are less concerned about the ethnicity and background of the person delivering them. One provider discusses an example where,

We'll have an African-American aide providing care to a Caucasian family...Let's say a month and that caregiver is saying she's like family because they're there and they're willing to help and they're asking what can I do and it doesn't take long to discover the client's routine, the client's ritual, and you're just a part of it (30).

Rural clients desire care providers to share the same ethnicity, but also accept familiar members of the community regardless of race and will use services delivered by those of different backgrounds once the quality service is established. Members of rural communities also value religious affiliation and common gender as an important element of care.

### **Black/African-American Clients—The Relevance of History**

Although there were agencies that served only one race, many agencies in both rural and urban areas served and were staffed by a mixture of Whites and Black/African-Americans. Providers from these agencies were able to compare the opinions of their Black/African-American clients and families toward staff persons of both ethnic groups. Like their peers in more rural areas, they see distinctions between the elders' and caregivers' attitudes.

#### ***Elders' Views of Ethnicity***

Most providers could not recall instances in which Black/African-American elders mistreated White staff members. However, some did sense a level of apprehension from the elders about the prospect of receiving care from a White person, particularly in Southern states. "I think that the older African-Americans...do not feel that a Caucasian aide should be out there helping them. That's something that has been embedded in them" (30). The provider went on to explain that, despite changes in racial attitudes in the general population, some Black/African-American elders were still influenced by the roles and attitudes that were common in their youth.

You [Black/African-Americans] don't mix period and certainly you don't ask them [Whites] to come in and help you at all because you are supposed to take care of them, because in the past a lot of African-Americans were housekeepers or nannies. So they were the ones going in and assisting the Caucasian families and so for the roles to be reversed, it's just difficult for them to even imagine that a **Caucasian** is supposed to come in here and assist **me**. I'm so accustomed to taking care of them (30).

The sense of inappropriateness in receiving care from a White person is not restricted to Southern elders. Similar attitudes have been observed in other parts of the country, perhaps due in part to the large-scale exodus of Black/African-Americans from the South in the late 1940's and early 1950's. A provider in the northwest comments that, "I see a lot [of] African-American older women from the South being very reverent to White staff, or other clients, and

you know, 'Yes ma'am,' and in ways that they have all their life, as they were working as a laborer for someone in their home" (46).

The flip side of this coin is the greater control over elders' problematic behaviors that White staff can sometimes exert by virtue of ethnicity. A Black/African-American daughter whose mother received in-home care suggested that her mother acted out less with the White staff than with her. The provider explains, "Her mother had always been a domestic, and had worked in White households, and so Whites were more of an authority figure and you kind of went along with the flow when there was a White person involved"(40).

Providers were quick to add that elders' reactions to White companions and staff members were less disapproving than one might expect. For example,

We had a [Black/African-American] client that thought it would be a problem because one of the senior companions that I had assigned was White, and the wife thought, 'I don't know if that's going to work. That might be a problem.' But once it started, the husband didn't even pay attention, having a White companion didn't even bother him (17).

### ***Families' Views of Ethnicity***

In fact, providers find that elders' families are sometimes more reluctant to be served by White staff than were elders themselves. The first barrier to convincing Black/African-American family members to use respite services may be getting past a lack of trust based in history. Several Southern providers cite the infamous experiment involving the Tuskegee airmen as an incident that destroyed some persons' trust in research participation and new programs. One generalizes,

In the rural area, the younger African-Americans are much more mistrustful of Whites than the older population...I think working with the participants is easier, White or Black. It's dealing with the families, because they're promised things. Just for instance, take the Tuskegee experiment. Trying to get them to take part in research programs and such as that...we had to establish a trust...Just for the researchers to go in and say, 'Will you participate in this clinical study?,' they were very hesitant because of history (40).

Although it may not concern elders, past racism is often well-remembered by family members. Lack of trust in White staffers can prevent Black/African-American caregivers from seeking assistance at agencies primarily staffed by Whites, in the opinion of some providers. A northern provider gives an example.

We had someone in adult day that told me that there's no way their mother would have been there if it wasn't for the ladies of color who work in day care. They would not have sent her...Here we are offering these wonderful services, but just because some of the staff is white, they didn't trust them to come (28).

As a result, some providers have seen racial concerns take precedence over convenience or proximity. In one area, White and Black/African providers worked in adjacent counties. The White provider comments, "Even though I work this county, she works the [next county], the [Black/African-American] individuals felt more comfortable dealing with [the Black/African-American provider] than going directly to myself. And the same with volunteers" (27). Other providers realize the importance of Black/African-American staff members in assuring that Black/African-American families will feel comfortable.

A few years ago they hired 3 or 4 people who happened to be of color and of this area, and that really opened the doors. That really was eye-opening to us, that because they [Black/African-American staffers] were going out with me and doing the home calls, or they actually knew the families, that the families were so much more trusting to have them come here...And I know we don't want to believe that it's as simple as that, or as much 'color' as that, but that's what happened (28).

### ***Care as Mitigating Factor***

Although families' attitudes toward staff members are influenced by ethnicity, providers saw trust as something that could be built despite initial reluctance. One provider explained, "I think we would have less people of color in the program if we didn't have staff of color...But once they're here and the families get to know us and they come in, it's just like we're a big family" (28). A program that meets caregivers' needs and a provider whom they can trust to keep promises can make up for racial differences, according to another provider.

I'm the only White in the room when I'm in [the rural community], and I feel like they have totally accepted me now to be in that position. The Black community up there is starting to accept me more, because they see that we're going to follow through with what we say (40).

Overall, members of the Black/African-American community express feelings of initial reluctance to accept a White care provider related to mistrust and social mores that have been ingrained for generations. In the same way White recipients are often unwilling to receive care by persons of other ethnicities. However, participation in the respite programs with individuals of diverse backgrounds often facilitated understanding and trust in the multiracial settings.

### **Hispanic/Latinos—The Need for Cultural Understanding**

In order to serve Hispanic/Latino populations, providers often stated that one must be familiar with, if not a part of, the cultures of Central and South America. This understanding is considered essential not only to provide culturally appropriate services, but also to enroll families in the first place.

#### ***Outreach Styles***

Providers stress the importance of outreach in increasing utilization of respite services among members of the Hispanic/Latino community. Staff members must go out into the community both to educate the population about dementia, and to raise awareness of assistive services. Several providers suggest that outreach, as the first impression families receive of respite services, must be conducted in a manner that inspires trust and implies understanding. In the opinion of one provider, “the importance in doing outreach...[is] to have people who are, number one, of similar cultural backgrounds. That’s important so that they feel this other person may understand their experiences, and also because of language barriers” (5). She, like other providers, stresses that families often feel that those with similar backgrounds will be more able to understand their feelings.

The inverse may also be true. Several providers mention that the more business-like approach of traditional outreach programs may alienate Hispanic/Latinos. Instead, outreach workers, regardless of their ethnicity, must understand and know how to work with the cultural norms of older Hispanic/Latinos. That can include taking more time getting to know the family and even relaxing guidelines of professionalism.

It matters when they send someone that is not culturally in tune, and thinks that knocking on the door, coming in and shaking their hand, which is a really normal Caucasian way of doing things, is going to get them the information they need. [For example], we’re all trained not to accept food and not to accept those kinds of things, but I’ll tell you, it’s a big insult to people if you don’t take one of their *bisquitos*. Reciprocity is very important for an older person (45).

A staff member’s background can also influence their efficacy as an educator. Some providers have found that educational programs for Hispanic/Latino populations were more successful when presenters were also Hispanic/Latinos. Hispanic/Latino audiences may be better able to relate to, and thus learn from, caregivers similar to themselves.

The basic step is to try to know them, the culture. For example, using their own language and using Hispanics for the [educational] program...Because [Hispanics] could

listen to African-American people or White people, and think it only happens to **them**, but [with Hispanic speakers] they realize it can happen in our community too (13).

### ***Communication Techniques***

Culturally appropriate outreach is only the first step to gaining the trust of Hispanic/Latino elders and families. The backgrounds of staff members also come into play in the design and provision of services. The most obvious issue involved with serving Spanish speakers is effective communication. Staff members need to be able to speak Spanish well enough to engage Spanish-speaking elders in activities. One provider relates an experience in which a caregiver was reassured by the presence of Spanish-speaking staffers:

I had a grandmother of a friend of mine that was Spanish-speaking, and that was a major plus to her that she knew that there was a Spanish-speaking staff. So she just didn't worry. She [had been] worried about her grandmother having a heart attack or needing to go to the bathroom and not being able to communicate and being incontinent, being embarrassed (43).

In addition to alleviating practical fears, Hispanic/Latino staff can provide comfort by sounding similar, in a manner in which elders are accustomed. In this respect, the psychological importance of cultural similarity should not be underestimated. "If they [elders] struggle to understand, if the accent is different, color is different, they can't open up as much. That's just the way it is" (13).

Providers can add to the comfort provided by familiar language by employing staff members that appear similar to the elder. One provider finds that same-ethnicity staff people eased elders' transitions into respite care.

If you can get in your staff, or one or two people in your client population, [people who are] African-American or Hispanic, and you bring a new person in, they see a like face. They see someone like them and it makes the transition into the program much easier (43).

Moreover, some techniques that would be effective for providing comfort to Hispanic/Latino elders would seem inappropriate coming from an Anglo staff member. Some elements of the Hispanic culture would not transfer well, according to a Hispanic/Latino provider.

In our culture we are so very affectionate. So you know, the love, hugging, the kissing. It can only be received from somebody that is from your culture and that looks like you. I tell them that it is important to have somebody that will mirror that population that you are trying to serve. Otherwise it doesn't fly (48).

### ***Mirroring the Population***

Recruiting staff members whose ethnicities mirror those of the target population can also inspire trust in family members. Another provider deliberately tries to maintain a diverse staff to preempt the perception of Whites condescending to minority populations.

We've tried to be purposeful in that, and have diverse staff that also reflects the diversity of the clients so that it doesn't look like a bunch of White social workers coming into the African-American community. We have a number of staff who are bilingual and that does make a difference. I think people probably still see it kind of as outsiders, but hopefully [the communities] will become more and more accepting of that (46).

Even within Hispanic/Latino communities, there are background elements that can affect perceptions of staff members. For one bilingual provider, speaking the same language does not always prevent judgements based upon perceived ethnic differences. Because she appears more White than traditionally Hispanic due to a unique background, she admits, "Because my color of skin and color of eyes are not like them, they are trying to speak with me in English all the time. So I really need to show them and deal with them over my color of skin or my different accent in Spanish" (24).

Class differences, brought over by immigrants from their native country, can also influence feelings about and levels of comfort with staff members and peers. An urban provider describes an example of class differences in her agency.

I did have one staff member who was from Colombia and was from a very class-oriented society, and was from an upper-class wealthy family, as was one of our clients from Colombia...It's an issue here, because I think with our Hispanic group we have some very very poor Mexican-Americans...and then we have the other class I'm referring to, and we try to deal with issues like that, where those class issues kind of enter into our small community here. So the one client will be trying to pay the other client for getting her coat for her (46).

Most providers agree that it is difficult to describe Hispanic/Latinos as a single group, as cultural and linguistic differences could be tied to particular countries and nationalities. This could mean that a diverse group of elders would not necessarily each be able to relate to a single bilingual staff member to the same degree.

### ***Working Around Ethnic Differences***

Although most providers agree that culturally similar staff members were preferable for Hispanic/Latino clients, they don't consider ethnic similarity an absolute necessity. In the opinion of a Hispanic/Latino provider,

When you care, it doesn't matter if you are purple or you are pink. The people respect you and at the beginning they will see you with a little bit of suspicion. You know, 'Is this person for real or what?' They are going to test you until they realize that you really care and that you really love them (48).

Ethnic similarity would smooth the transition, but mutual respect could occur without it over time. A White provider in a rural area has similar feelings about the language barrier between herself and the clients. She finds that despite ethnic differences, her attempts to learn the Spanish language and culture carry weight with the clients.

I have not met anyone in the Spanish-speaking population that has not been willing to teach and assist in overcoming the language barrier. They are very happy that we [White staff] are trying to learn their culture and their language, and it makes for an extremely rich environment (44).

A Hispanic/Latino provider affirms the idea that intentions are more important than ethnic similarity.

Forget the looks, because in the Latino culture you've got every color. Every color you want from the blondest, blue eyed person to the darkest person...So it doesn't matter almost what you look like because if you come out and you look just like a person, and then you don't understand what this person is talking about, forget it. Throw it away. You've got to feel it...you've got to understand (4).

Providers that are familiar with, or a member of, the Hispanic/Latino community and share a common language are the preferred staff members by this cultural group. Recognizing differences within this ethnic group is also important since class stratification and linguistic differences prevent treating all Hispanic/Latino persons like they belong to one homogeneous group.

In summary, it is apparent that members of each cultural group prefer to be served by providers that have looks, language, and values in common with them. However, these preferences can become secondary as families come to appreciate the assistance that respite can bring and understand the genuine caring of the staff.

#### **RESEARCH QUESTION #5: WHAT BARRIERS TO SERVICE USE HAVE BEEN IDENTIFIED FOR THE TARGET POPULATION?**

Providers face barriers common to serving dementia families, as well as barriers that are specific to the geographically and ethnic challenges. Difficulties in service delivery can be experienced at both agency and individual levels. Across the three cultural groups under study, there are both shared and unique issues to be addressed.

### **Agency Level Barriers**

At the agency level, funding, cost, staffing, and transportation needs represent a continual struggle for providers to overcome.

#### ***Scarce Resources***

Although each provider's agency receives grant funding through the ADDGS and other sources, these monies are often enough only to provide base-line services, and then not for the entire population. One rural provider laments the impact of limited funding on timely delivery.

Lack of funding...is definitely the top one [barrier], and being able to serve people immediately...Sometimes the funding sources...have waiting lists and you can't piggy-back, or once they get off the waiting list they are not able to get all of the services that they would need to stay in their home independently and safely (18).

At times when enough funding is available to serve all who need it, purse strings are still tight when it comes to affording supplies and materials to facilitate activities. This does not always preclude desired activities, but it challenges providers' ingenuity, according to another provider.

Money is always an issue...We're on a very limited budget, so we have to be very creative. At some times, we'll have a certain activity that we'd like to do, but to buy the materials for that number of people is very limiting (31).

Another provider in an Black/African-American community says that she has enough money to provide basic services, but finds it difficult to have enough money for extra touches.

Funding is definitely and always an issue...We generally have to be creative in doing fund-raiser type activities to be able to provide adequate supplies and things to them (9).

Developing a stable and adequate funding stream that is necessary for service provision is a universal barrier mentioned by almost every staff member interviewed.

#### ***Cost and Affordability***

For some caregivers, desire for respite services may not be enough to guarantee utilization. They may have to confront other barriers, such as lack of income or structural issues. Many caregivers do not have the resources to obtain assistance on their own. For example, a provider in a Black/African-American community describes the challenge of setting up home care.

Once we're referred [families] to [home care agencies], and they come back to us, it's like, "It's too expensive." The financial part of them caring for or getting help to come into their home for a short period of time is really overwhelming to them (10).

Although many programs are able to offer a few free slots to needy families, the need often outpaces the resources to create more slots. A provider has had this problem at her day care agency.

What we have found the problem to be is, we only have eight slots that are available without cost to the families. And we do not have nursing staff, so we're not eligible for any medical subsidized programs. Therefore, the reason that the people in our community do not utilize our services and we have some vacant slots, is economics. The families cannot afford to pay for the services (38).

In some rural areas that are characterized by low socioeconomic status, providers view non-use as a function of cost. One provider explains,

In our area, people don't have a lot of money...So when you say adult day program costs \$8 or \$9 an hour, up here people are flabbergasted. They never made that much money in their lives; they can't possibly understand how anybody can afford it. So it's the affordability of the day service program that keeps folks from utilizing it (21).

An additional barrier is the expectations of families who are unwilling to even make a contribution. Some families are unaware of Medicare payment restrictions, and are dismayed to find that they might have to contribute funds to cover the elder's care. Communicating policy restrictions has been a challenge for one provider.

You stress it's a voluntary contribution, but you're still saying it's an expectation they can pay. So say they say, "I don't feel like I can afford this." So we lower the fee. We try to work with them but there've been cases where they really don't want to pay anything. They can't understand...it's not completely and totally covered by the government and a lot of families think that Medicare is going to pay for this type of care (11).

In other cases, families have become reliant on the elder's income, and are reluctant to seek services that they think might jeopardize this financial resource. One provider observes, "There is also often a financial incentive to provide care within the family system because the grandparent's Social Security or income becomes important to the household... The minus is that sometimes it is too difficult to manage at home or the care is really marginal" (43). Another provider has encountered situations in which financial need has overshadowed care needs.

Some people ...Some of them, they don't care. To be perfectly honest, granny is a paycheck. [She] is a Social Security check and that's it. And if they don't have to extend too much effort to get something done, then that's okay, but if we're going to have to get up a half hour early to get cleaned up and dressed, "Well, I don't know" (14).

Thus families' ability and willingness to pay for respite services remain barriers in many communities.

### ***Staffing Issues***

In addition to the struggle to maintain program funding, many providers also mention difficulties in finding and keeping a sufficient staff. Populations are small, and distances between cities are

often large in rural areas, which can make finding workers particularly difficult. In some places, this can be compounded by demographic shifts in the number of working-age people.

Finding staffing to go into some of these very isolated areas. We have a very high percentage of older people living in the county and a very few younger people...It does become a challenge to find workers in the very rural areas, and those people need as much help as people that are located in a more urban area (18).

Another reason for current staffing shortage in aides may be a combination of low wages and a booming job market. A provider explains, "A lot of that, of course, has to do with unemployment rates are very, very low, and with a lot of agencies people receive not nearly enough per hour and there are no benefits. So staffing alone has been a great challenge" (22). For in-home respite providers, the job description could have as much impact on the shortage as economics.

The other barrier for the in-home respite program is the staff. It is so hard to keep home-care aides nowadays...I think it takes a special kind of person to do this...and it is a tough job (28).

### ***Transportation Issues***

Transportation is most often seen as a rural challenge; however urban providers mention it as well. It can also be a financial barrier, for both aides and clients. Although providers in many large metropolitan areas did not consider transportation a widespread problem for clients, one agrees that it can be a problem for in-home aides who had to go to several homes.

Many of the home care aides are from a socioeconomic background where they can't afford a car. They cannot afford a car and so to get to a case that is not located near a subway or bus stop is extremely difficult...I could see it's a barrier to many areas of the country to operating this type of system (11).

Smaller metropolitan areas face even greater obstacles to transporting clients. One provider views her agency's transportation contract as a limiting factor.

We contract for transportation...That limits the distance we can outreach to, and it also causes us to have to pay more attention to the kind of outdoor activities that we can have in terms of field trips we can have, because that is an added expense each time we put our clients on the bus and take them to activities (38).

Transportation is most difficult for the more remote families. Rural agencies are often unable to provide transportation widely. Demonstration providers believe that there are many families who might want to use services, but for whom transportation is the central barrier. "We have the county transportation that picks some of them up, but we do have some that are in the far end of the county that it would be kind of hard to get them here for transportation purposes" (34).

Other rural areas lack even a rudimentary countywide transportation system. A provider in one such area laments, "Even though we're rural and transportation is a huge issue out here, we have not had a successful transportation system" (27). Structural barriers like these can prevent even the most motivated potential users from becoming clients.

### **Other Shared Barriers**

At the community level, providers find a pervasive mistrust of institutions and a general lack of awareness about respite services. This lack of knowledge and mistrust includes fear of the government, distrust of bureaucratic procedures, and fear of the medical community.

#### ***Mistrust of Institutions***

Ethnic minority and immigrant families face special barriers to utilizing services. In rural areas where a recent influx of immigrants from many countries has occurred, some new residents' fears of governmental bureaucracy prevent them from accessing services.

For some [immigrants]...it's been a great challenge for them to jump through all those hoops to come to this country. So there's a certain sense of mistrust there, because how do they know that the government here isn't like the government in their own mother country? (22).

In urban areas where there may be family members in this country illegally, providers face additional challenges. For undocumented immigrants, fear of the US Immigration and Naturalization Service pervades their attitudes toward government assistance of all kinds. They see service use as contrary to their desire to maintain a low profile. According to one provider, "The people who are undocumented...[are] fearful that somehow the Immigration or the government is going to find out they live at this house or at this address, and that starts the reluctance right there" (3). Another provider attests to the pervasiveness of this fear, even for immigrants who are in the United States legally.

[Undocumented immigrants] are not allowed to work in this country. So they expand that fear to everybody and everything and every matter...But it's not every family that are undocumented, it's here and there. But they fear the establishment even if they are legal already (24).

The bureaucracy associated with applying for services can be another barrier to utilization. Some caregivers feel intimidated at the mere idea of going to a government building to fill out an application. A provider explains,

A public office such as the county department or the Social Security office, it's very intimidating. The protocol for how you act to the services and the language is very difficult. So it's kind of intimidating for the client (3).

The application form itself can be equally daunting. The same provider found that the length and extent of the questions can prevent Hispanic/Latinos from receiving the services to which they are entitled.

You go to apply for SSI for like a 15 page form for Social Security. You go to apply for Medicare with L.A. County, and it's another 20 page form. It's very hard to get through this paperwork...It's very hard to bring documentation like your earnings, your bank account, your rent receipt, your utilities. A lot of times the bills are paid in cash so it's very difficult to get through "the system" (3).

In some cases, Medicare is the only payment option available for a needy elder. The degree of difficulty and the extent of the paperwork and documentation can act as a barrier.

### **Distrust of Western Medicine**

All communities mentioned difficulties with finding competent, trustworthy medical care for dementia issues. However, for the Hispanic/Latino community, this challenge is addressed culturally with a preference for folk remedies or alternative medical treatments over Western techniques. More common among spousal caregivers, use of home remedies and religious devotion often go hand in hand in this community. One provider comments that a combination of religious fervor and tight finances can lead caregivers to use home remedies.

Our cultural challenge would be the religion, the home remedies...There is a very strong belief that God is going to help me. God is going to answer me and my prayers will share my burden...If they don't have medical, if they can't pay for a medicine for a particular illness such as Alzheimer's, they will cure their person with their own remedies (3).

If they had the means to choose, many older caregivers would still opt for traditional medicine. In fact, another provider has observed that people go out of their way to find the proper ingredients for a medication. "A lot of people will go over the border and buy certain medications because they're not sold here, because they're going to do it the 'right way'" (4).

Other providers feel that the practice of folk medicine has less to do with its benefits than with reluctance to use Western medicine. According to an urban provider, many Hispanic/Latinos are not raised to value preventative care, and are not accustomed to regular doctor visits.

When I make the schedule for doctors' appointments, sometimes they say to me, "Oh, I am OK. I don't need to go to the doctor, they're just going to say that I'm OK."... So that's another problem I am fighting, because we are not educated to go in for a regular check-up, you know. We just went to the doctor when we felt sick (47).

Lack of funds can perpetuate this phenomenon, and discourage familiarity with the medical system. Another provider adds, "With limited income, it's less likely that you've had preventative medicine throughout your life, it's less likely that you had many interchanges with doctors, so maybe you're not familiar with what might happen in a medical setting" (5). This lack of familiarity with the medical process can lead persons to irrationally fear an adverse diagnosis because of their view of what it represents. A staff member explains Hispanics/Latino's fear of doctors.

I think they are afraid for the bill, first. And there are other things, like they don't want to face if something is wrong with them...For example, I have a client who has a problem with his prostate, and he says that means that he isn't really going to be a man if they remove the prostate (47).

### **The Medical Institution**

Providers routinely mention difficulties families have in interacting with local physicians. Many staff members report reluctance on the part of family doctors to diagnose Alzheimer's disease or to refer clients on for further testing. Potential clients, without formal diagnoses, are less likely to seek respite services.

In Hispanic/Latino communities, providers report a lack of physician diagnoses or accurate explanations for dementia symptoms. A common problem is the misdiagnosis that dementia is an inevitable part of aging. A staff member complains, "Doctors will tell them there's nothing you can do about it, he's old, this is the sign of aging" (4). Another provider from the same area was quick to add, "And so the families see it as something that's inevitable, and something that they really can't seek help for" (7). Because they do not identify memory problems as Alzheimer's disease, or even if they do, physicians are unlikely to refer families to a dementia-specific portal agency that could point them toward respite. A provider affirms this observation.

Even the doctors don't recognize what is going on and sometimes they say—most of the time they say—well, yes, your loved one has Alzheimer's without doing any test and they send them home and say, well try for that person to have the best life they can. But they don't say you can call the Alzheimer's Association, you can get some information and some help (13).

Providers indicate that Spanish-speakers are particularly handicapped in this situation by minimal English-language abilities. One staff describes Hispanic/Latinos' difficulties in asking follow-up questions.

They go to their doctor, and maybe because the doctor doesn't speak their native language, they feel intimidated. So they don't confront the doctor, they don't ask them, and/or the doctor at many times is not educated about dementia, so...they don't go that extra step (7).

Even if they were not satisfied with the diagnosis, providers found many Hispanic/Latinos reluctant to seek a second opinion or visit with a specialist. This can lead to an elder remaining undiagnosed, and not receiving appropriate services. According to the same provider, this is due in part to a desire to maintain a relationship with their long-time physician.

A lot of these doctors, they're the doctors they've had for 20 or 30 years, and the family is very attached to these doctors, so they don't want to seek the help of a specialized professional and/or receive diagnostic testing. That's a big barrier, because without the doctor working together with the family...a lot of times families go on with their folks being undiagnosed (7).

In rural areas, families face similar challenges. Some rural providers attribute the reluctance on the part of physicians to make a diagnosis to their own lack of understanding about the disease and the diagnosis process. One provider feels that, as doctors' time with elders decreases, so does their ability and inclination to accurately diagnose Alzheimer's disease.

I don't think dementia is easily evaluated in 20 minutes in a doctor's visit and I think more and more doctor's offices that's all they've got is 20 minutes. I think early dementias are not picked up because folks typically do very well when they get themselves together...and can really cover quite well...I think on one hand the physicians don't have the time and I think sometimes they don't take the time and I also believe they're not well-educated (19).

Other rural providers have found that, even when a positive diagnosis has been made, physicians may not disclose the exact diagnosis to the family. This can be a barrier to service in agencies that require a diagnosis of dementia before an elder can qualify for services. Another provider shared this view.

Some doctors won't tell families. In order to get on this program, we do have to have a diagnosis from the doctors. And when I've asked for that, the family says, 'Well, the doctor's never said anything like that, but she certainly is having a lot of memory

problems. And we've asked the doctor but he's never told us.' And sure enough, when that diagnosis comes through over the fax, that's exactly what it says, it's Alzheimer's or dementia (21).

Even when willing to both diagnose Alzheimer's disease and inform the family of the situation, physicians may not understand the value in referring elders to respite programs. A provider in rural area described her efforts to obtain referrals from local doctors' offices.

We have been trying to get these primary-care physicians to refer people to us for a free program...I took packets out to three major physicians in the county, sat down and talked to their nurse managers...and I asked them to please refer eight people, out of ten packets I gave them. Now, you're not going to tell me that all those physicians didn't have at least eight people with dementia that would need some information and referral...I have gotten no names, none, and that was a year ago that we went out and asked them (28).

Providers in Black/African-American communities assert that, by not familiarizing themselves with Alzheimer's care, today's doctors are doing little to remedy this problem. One provider maintains that even when medical care is sought, physicians sometimes perceive dementia as untreatable and recommend nothing. "Educating across the board, and the lack of it, is a real drawback. Having physicians who won't recommend things because it's not going to do any good anyway" (39).

For the Black/African-American community, a more commonly encountered barrier to service use is mistrust of physicians and the medical system. Providers in both urban and rural areas report that some Black/African-American families treat health care providers with suspicion due to past exploitation. One provider sees that past maltreatment has led to residual mistrust.

It's been a historical fact that African-American people have been exploited. They have participated in events, and have been taken advantage of...There is a big trust issue in this community (26).

A Southern provider cites the specific example of the Tuskegee experiment.

They [Black/African-Americans] turn down opportunities because they are suspicious that it involves more than what is being presented...The Tuskegee research project is seen as a medical thing. And that research project not only I think affects African-Americans in research, I think it has an effect on African-Americans in medical treatment (39).

Additionally, some providers believe that families are reluctant to use services or trust providers because of past, personal experiences as well. This is common particularly for older persons

who may have been previously treated dismissively by physicians and had their complaints trivialized.

They haven't had things explained to them where they could understand them in the medical system in the past. Words are used that are not common to them. Full descriptions aren't given because there's an assumption that they wouldn't understand (39).

### ***Lack of Awareness of Respite Services***

Providers suggest that another barrier caregivers face is lack of familiarity with services. Some are completely unaware that respite is available. "That's the number one problem that we have in this type of community, and with this type of service, that they're not aware that there are some services out there that are available to the caregiver" (16). This is most often the case with caregivers who work full-time or are overwhelmed by caregiving tasks and have little time to investigate care alternatives.

[It's hardest to reach] ... daughters, or those who work, who's trying to just take care of them, get help during the day or just leave them there at home and try to come home from work, take care of the kids, take care of Mama and really don't stop...to whom no information has been presented because they're so wrapped up in their day-to-day life, working and coming home, taking care of their loved one (10).

This lack of awareness can lead families to find respite services too little, too late. Since some respite programs, particularly day cares, can only take elders who are ambulatory, the advanced condition of elders can also be a barrier to service. A day care provider laments,

My barriers are I'm really not supposed to serve you unless you're in the early stages. And when we get the call, usually they're in the middle stages, and that's really sad. They went two or three years and didn't call for help. "I thought I could manage it," but they waited too long (17).

A related barrier is caregivers' denial of the true extent of the elder's illness. The gradual progression of the disease makes symptoms easier to ignore.

Gradual change, change over time is not noticed nearly so much. And also because a lot of times I don't think people really know what to do. A lot of times things are seen as personality, not disease (39).

Even if they have some knowledge of respite, some caregivers face difficulties in accessing care. Without guidance, they can get lost on the way to inquiring about respite. A provider describes an example of how impenetrable the bureaucracy can seem.

[A caregiver] had been trying to find out what was available for people who had dementia...and she had taken the day off from work, and had been calling continuously since 9:00 that morning before she got to me...Either she always got the wrong person, or the question she asked wasn't phrased so that they could give her an answer. But

the fact of the matter is, she called all day long before she got me, and found out how to just get day care, in-home respite, and that kind of thing (39).

### **Culturally Specific Barriers**

In spite of the many barriers that were common across all cultural groups studied, there are some challenges that are culturally specific.

#### ***Rural Families***

In rural communities, providers faced a strong desire of families to maintain their independence and a sensitivity to the potential embarrassment that can be caused by dementia-related problem behaviors.

#### **Ethic of Independence**

Lack of support from the medical community is one of several factors that might keep families from seeking respite services. Elders and families might be reluctant to inquire due to personal reasons, or language difficulties. Providers mention that in rural areas, where a strong work ethic and independence were highly valued, older persons might not want assistance nor would they feel comfortable asking for help. One provider observes, "These people...were never dependent on anyone else to do things for them...and they find it very difficult to ask for help in any way, any form" (34).

#### **Shame and Embarrassment**

Since there is a heightened sense of familiarity in rural communities where everyone knows everyone else, the potential for embarrassment due to dementia symptoms is great. The elder's level of disability and severity of symptoms can influence whether a caregiver will use the services or not. Families of elders who act in a disruptive manner may feel that respite, particularly a day care environment, is not an option for them. This can be frustrating to providers. "Seeing caregivers really stressed out but unwilling to accept the services, saying, 'I don't think he'd like it,' or 'He'd be upset,' or 'His behavior's so bad I wouldn't want to leave him with you'" (23). Others find that while families might try respite, issues surrounding dealing with problem behaviors can cause them to discontinue services.

#### ***Black/African-American Clients***

Many Black/African-Americans' express a strong preference to keep their elder in the community.

### **Preference for Family Care**

Families sometime view service use as the first step toward institutionalization. One provider sees this attitude in regard to her day care.

The families are the problem, because they're in denial of what's happening. They want to keep that person as protected as they can keep them, and they do not want to send them into a day care, because when they walk into a day care, it looks like a nursing home to some of them. They say, "I don't want my Mama here, my Mama's not that bad" (17).

Although familial care is highly valued in theory, the bulk of care still falls most commonly to one family member. Ironically, this stress of caregiving without assistance can lead to early placement. Providers have seen this happen due to lack of extended family assistance.

Most of the time it's lack of support. You've got one family member, usually a daughter or a son, that's doing all the work. When a challenge hits them personally on their jobs or whatever, then everything breaks down for the client...That family member has to make that drastic decision and most of the time I've got to put Mom or Dad in the nursing home because I can't keep them at home. Therefore, I lose them on my attendance (9).

### ***Hispanic/Latino Families***

Along with many of the barriers already mentioned, providers who serve Hispanic/Latinos face barriers specific to the diverse national cultures of this population.

### **Familial Duties**

Several providers spoke of caregivers' feelings of familial duty as reasons that they might not seek services. One explains, "They're not really high utilizers of service because they depend on their families to care for them; there's a very inter-woven idea that the family has to care for them" (7). Enmeshed with this belief of family care, seeking services is often seen as complaining about their family duty. According to another provider, many caregivers view it as wrong to complain about doing one's duty, and therefore, wrong to try to find assistance.

There are very many barriers. One [is] not wanting to complain, thinking that it was wrong. To say "I need help," because they felt that...you suffer in silence. It is your duty, so therefore why complain? (4).

This is especially true for eldest daughters, who, as the culturally appointed caregivers, are more likely to feel personal and societal guilt at not performing these duties. As one provider said,

It's one of the reasons why Latinos are also not likely to seek help for a while because they assume that the elder daughter [will provide care]...they assume "This is my duty,

this is what I am supposed to do. It would reflect poorly on me if I seek help. I would be a bad person" (5).

### **Services in Familiar Surroundings**

Another reason some Hispanic/Latino caregivers are reluctant to seek services is fear of disapproval and alienation from the population outside of their neighborhood. A provider in Los Angeles finds that families were sometimes unwilling to use services that are not in the immediate vicinity of their home. "Especially in Los Angeles County, there is a huge geographic area, and there are many people who are afraid to venture outside their community because they don't believe that services outside the area will be friendly or accessible" (5).

Hispanic/Latino caregivers also do not feel comfortable with some of the programs that help White caregivers, and so are unlikely to seek those services. A provider describes the reluctance to attend support groups. "I think again it's a cultural thing; to go to a [support] group and talk about your problems is not something that they are generally real comfortable with doing" (50).

### **Language**

Language is a clear barrier for both medical professionals and providers. Lack of a common language can prevent families from seeking services, or cause them to discontinue services after a short time. A provider speaks of the need for Spanish-speaking workers. "If you have services, and they're not provided in a culturally sensitive manner with appropriate languages for their loved ones, it's a barrier because they're not able to understand the process" (7).

Another factor that is important to keeping Hispanic/Latinos involved in respite is cultural appropriateness. Staff people who are unaware of cultural differences between Hispanic/Latino groups might constitute a barrier to service, according to one provider. "I would say for myself the language barrier has been number one, and then the cultural difference in appropriate communication versus inappropriate communication that's specific to the Spanish [speaking] culture" (43).

The communication barrier can even be more extreme in rural areas. "Probably the biggest issue is the communication...It's pretty hard to help somebody if you can't communicate with them" (22). The situation is compounded by the isolation and often limited resources in small cities and rural areas. A provider serving a community whose minority population has increased rapidly finds it hard to find translators and learn about cultural diversity.

We have a very diverse population in this area; believe it or not, even though we are very rural...It's not like a city where you have 100,000 people in one spot. Because of that, the numbers that we have representing one [ethnic] population are much smaller...So it makes it more difficult to find the resources because the population base isn't there to be able to pole other people who can speak languages or know a lot about the culture (18).

### **Barriers to Service Use**

Providers face many common barriers. At the agency or program level, providers need to cultivate stable funding mechanisms, address clients' willingness and ability to afford the costs of the services, hire and retain quality staff, and attend to transportation needs. Other shared barriers include the pervasive mistrust of the government, difficulty in interacting with the traditional medical community, fear of bureaucratic forms and information seeking, and a general lack of awareness about respite services.

Each community also has barriers specific to their cultures. For rural families, it is the belief in an ethic of independence and self sufficiency as well as the sensitivity to embarrassment due to dementia symptoms. For Black/African-American communities, providers faced a strong preference for family care and a belief that any service use was a step toward institutionalization. Hispanic/Latino communities also promote a strong family care norm and most often do not seek assistance with care, as that is the traditional role of the eldest daughter. The lack of respite services located in Hispanic/Latino neighborhoods, coupled with the cultures' distrust of outside communities, decreases service accessibility. Additionally, Hispanic/Latino families faced communication and language difficulties.

### **RESEARCH QUESTION #6: HOW HAS SERVICE DELIVERY BEEN MODIFIED TO ADDRESS IDENTIFIED BARRIERS? HAVE THESE EFFORTS BEEN SUCCESSFUL?**

Many providers had developed particular program and outreach modifications to address the barriers they had identified. The majority of these solutions are applicable across cultures, while some are culturally specific. The providers offered concrete suggestions for creating successful strategies for serving diverse populations.

### **Talking about Respite**

Providers found that how one talks about respite services is important. In order to address caregiver concerns about using services, providers need to choose their words carefully. Some providers believe that families need to feel like it is okay to use services.

Providers find that an important first step is approaching caregiving families in a manner that is non-threatening and supportive. One provider often meets with success when she emphasizes that getting assistance does not mean that a caregiver is weak, but instead using respite services can prolong informal caregiving.

Somewhat it's also giving people permission. Sometimes people need to be told, "You can't do this anymore. This is too hard, it's hurting your health"...Not to point out that they're weak, but that they're really strong but they need to keep that way (23).

Providers also express the need to make caregivers aware that using respite does not mean that they are surrendering their caregiving role. Instead, another provider finds it helpful to work with the family to provide a comprehensive package of care.

We have had to take the approach...that we are not there to supplant the family. We are there to complement what they're doing, and we try to develop some type of team approach with family members so they realize that we understand that the care that they're providing is excellent (18).

Several other staff members expressed the need to communicate the idea that they are there merely to help the caregiver do her job better, nothing more. In the experience of one provider, when respite is properly explained, caregivers feel less guilty about using it.

Anybody can give people physical support and take care of them for their actual physical needs...Only the person that's the closest to them can give them the emotional support on an on-going basis...If you're exhausted by the physical, you can't do the emotional. And so to use other sources to help you with the daily care, you can then do your job better (39).

Providers in Black/African-American communities strive to avoid the implication that they're coming in to "take control" of the elder's care. One describes her personable approach to an initial meeting with a family member.

I try to start a conversation about something they'll relate to. Pick something in their house, or something to talk about, or the baby, or I try to get on a friendly term so that I am not just some lady coming in from out of nowhere to tell you what to do. Under no circumstances would I ever want them to think that I am there to tell them what to do. I am there for them to tell me what they need and then to see if I can do it for them (14).

Since many Hispanic/Latino caregivers feel duty-bound to provide care, and guilty about asking for help, some providers de-emphasize the idea that respite is for the caregiver's benefit. One provider stresses that service use is participation in a research study that will help providers learn more about Alzheimer's disease (4).

Providers saw that caregivers were also reluctant to let outsiders know about their elder's condition, particularly if problematic behaviors were present. One provider found it helpful to discuss the prevalence of dementia in the general population, to demonstrate that no family was alone or should feel ashamed.

I think the best way is just to tell them, to show them research, and say, "Did you know that so many families are experiencing this?" And whenever they come to the day care where I'm currently working, I let them know, "All these people in this room have dementia. You're not alone, and your wife is not alone," because sometimes they don't want to bring them to a service because they feel they're going to be disruptive of the other people (7).

### ***Creating a Comfortable Respite Environment***

Providers also note that the appearance of the respite environment can speak volumes about the care philosophy and how "institutionalized" the care will be. Caregivers should be reassured by the appearance of the care center. Providers mention the importance of a home-like atmosphere to families, particularly families who are adamant about avoiding institutional placement. One provider, who took time decorating her day care, received positive reactions.

There is no resemblance to any kind of institutional care. We have volunteers who are a part of our services, and they decorate the rooms for the clients. Twice a year they come and look at the rooms to make sure that they are as they should be. And I think this is why the clients that we do have are on-going clients, because the families feel very comfortable in the kind of surroundings that they are in (38).

### ***Familiarity***

Because familiarity plays such an important role in rural areas, several providers use their ties to the community to convince families to accept respite service. One quickly learned that a friendlier and less professional approach works better at the start of a relationship with families.

I save [the] complicated pieces [of information gathering] for later. I will go in and because the communities are so small everyone wants to know who you're related to. That's been very helpful when I say, well my grandfather was the barber in the town, and everybody knew my grandfather, and then all of a sudden there is a comfort level there. So I am already part of the community. It's a community they're familiar with and I am no longer a stranger (18).

Although being a long-standing community member helps increase comfort, providers who do not have that advantage can still make the most of small-town familiarity. Another provider has found that, even though she is not familiar to clients, her volunteers often are.

One of the things I do on the initial assessment to kind of ease the caregiver's mind and the patient's mind is to say, "You know, I do have a few volunteers who live out in this area," and I would rattle off their names, and I would see if any of them ring a bell. Maybe they know somebody through somebody through somebody else...and we would pair them right away because they have that familiarity. And I would find that those pairings would work so much better (27).

### **Cultural Similarity**

Environments must be comfortable for the elders as well as the caregivers. This may be even more pronounced in the Hispanic/Latino community, but is important to address for all communities. Providers suggest other ways of helping elders feel included that also create an atmosphere that can be fun for all. Several people mention the necessity of serving familiar food. One provider found, "The foods that we served were foods that they were familiar with and so they liked that they were eating rice and beans or something like that" (1). One provider that serves a diverse group of elders has to make a special effort to provide culturally appropriate food, as the food they normally receive for the day care is rather Americanized.

We try to have more culturally acceptable foods that they like better, on at least some of the days that we have a higher group of people from our Hispanic community. We'll go to local restaurants that serve different foods that they like, and try to have some different meals here other than what we normally get from the Meals-on-Wheels program, which is pretty much geared toward meat and potatoes and vegetables (50).

Celebrating the holidays of many different nations makes Hispanic/Latino elders feel at home, and is also enjoyable to non-Hispanic clients, according to one provider. "Knowing that we had people from different countries and there seems to be a lot of pride in that, and so we would celebrate anytime there was some sort of...independence day, and they really enjoyed that" (1).

### **A Service, Not a Handout**

Another part of caregivers' reluctance to use support services was that they perceived the services as Welfare or a handout. Providers mention that charging the clients a nominal fee for services alleviates much of this resistance. One provider relates the success of this approach.

A lot of people in this area, because of their pride, want to contribute financially, and we've found that's been kind of nice when people can give what they feel they can afford toward the care that they're receiving. They feel better about the care that they're receiving...So I don't care if it's a dollar, I don't care if it's just 50 cents, as long as they're contributing something (18).

Striking a balance between affordability for the family and payment for service can be a successful strategy for increasing the level of comfort.

### **Cost and Affordability**

A final barrier that providers attempted to address was that of a lack of income. The bureaucracy of the social service system prevents some caregivers from applying for government programs that could help with costs, so some providers work to help clients access the system. A provider explained,

I will help them fill out the applications. I will try to help them gather their receipts and their papers. Sometimes it's a little difficult because their book system is not...the best, but I try to encourage them on how to do it (3).

For families for whom this is not an option, providers stress the need to use a sliding fee scale that allows needy families to get the care they need. One describes her agency's policy, "Certainly all our services are on a sliding fee scale and if they can't pay today the \$10 minimum, then that's fine, we'll bill them for it" (45). Providers realize that a well-designed program of care means little if no one can afford to use it.

It didn't matter that we had done all the work if that older person would have gone to our partnering agency and could not have paid the minimum. And they couldn't, they would not have gone. So we could have had the best program in the world with [only] one attendee who could afford to pay (45).

### **Program Responsiveness**

Providers report that when they modify their programs to address specific family needs, clients are more likely to begin and continue service use. Some providers find it helpful to set individual programs for clients once their personal needs are known. One provider has been successful by individualizing her approach to each client, which seems to keep them coming back to day care. "What we've done is just be creative all along on an individual basis...We had a lady that didn't want to come, and what they would work out with her is they would set it up where it was a job, and she was actually going to get paid [for helping out at day care], so she was really interested in that" (31). Rural elders who are used to hard work may find productivity more palatable than recreation, and providers can use that to their advantage.

Providers also suggest modifications that they have made to counter elders' resistance to attending day care programs. Providers comment that the manner in which they frame day care services is important to elders' willingness to attend. Sometimes providers' choice of words alone could make a difference. One provider refers to her day care as a "club".

We refer to the fees as "tuition"...That's the way we let the people think of it. It's more acceptable that way...because most everyone has belonged to [a club], whether it's been a civic club or a social club or a church group...So there really is a different way of thinking when you refer to it as a club (40).

Another provider oriented her day care in the same way, and felt that Black/African-American elders saw it more positively as a result. "You're coming here to socialize, you're not coming to a day care, you're coming to a socialization group where you're going to come and socialize with friends that you've met" (17).

### ***Modifying Activities***

Providers also suggest modifications that they have made to counter elders' resistance to attending day care programs. They found that over stimulation could be a problem, and that few programs appealed to all elders, which were both reasons that caregivers might discontinue respite care. One provider mentions that being flexible in the activities that are planned for a given day, and being responsive to the moods of the elders, can prevent over stimulation.

We may have a certain activity set up that we were going to do...and we need to change. Instead of having a hands-on activity, we may need to change it to an exercise. They may be over stimulated that morning and instead of singing after lunch we might have a movie just to do some calming, so not only on a monthly or weekly basis, but by the day and the hour, what you have might have to change (31).

The kinds of activities for the elders are also important. In general, familiar activities are favorites with day care clients. One provider adjusted her offerings to correspond to the religiosity that is common in Black/African-American culture. "Most African-American elderly people have a very high...spiritual background, so we do have a lot of programs that are geared toward that. We also do Gospel and Bible hour here" (9). An activity that goes hand in hand with a religious orientation is the use of hymns to sooth and entertain elders. Providers see music as an activity that can appeal to elders in all stages of illness. Another provider finds music to be quite popular.

We play music the whole six hours...so that if we have someone progressing in the disease and they can't really function, they have music. We used to start out with nothing but gospel, but now we play music of the '50's and the '70's, and everybody knows that music because that's their music (17).

Although these activities seem to appeal to the majority of elders, providers cautioned that they still need to think about the needs of each client individually in order to provide the best care for them. As one staff member mentioned, "We deal with each one as an individual and try to meet their needs" (14).

### ***Accommodating Working Caregivers***

Providers perceived a special barrier in reaching and serving caregivers who were also employed full-time. Several put forth extra effort to reach these caregivers. One provider has had success reaching working caregivers by doing educational presentations that did not interfere with work schedules.

We try to do workplace education seminars, and we would go...and do a lunch time program on Alzheimer's disease, because a lot of the people, they're not going to come to a "special program" if they are caregivers. For a lot of them, once they get off work and go home, that's when the caregiving starts...So we can go in to a workplace, do our program [as] a brown-bag lunch where they're not losing any time from their workplace (8).

Once providers reach working caregivers, they also need to adjust services to accommodate tight schedules. Another provider was able to extend her program's hours to facilitate use by working caregivers.

We have extended hours here because most of our family members if they are daughters or sons, they're still working class people. So we have extended our hours longer than most day care programs. We're open from 7:30 in the morning until 5:30 in the evening. That makes it easier for them to drop their family members off early and to pick them up after work hours (9).

### ***Reinventing Support Groups***

A related barrier is caregivers' resistance to attending support groups. Some do not feel comfortable with the concept, and others have a difficult time fitting it into their schedules. Providers have tried several strategies to increase support group attendance, with mixed results. One provider had attributed low attendance to the lack of an alternate caregiver to stay with the elder, and so explored scheduling alternatives. "We're trying to hold our caregiver support group meetings during a time where the caregivers can bring their loved ones to the adult day care program...but we're still having low turn-outs, so we're going to have to rethink

this” (26). Although this idea has not yet played out, the provider sees the need to keep trying until something clicks.

Another provider has seen great increases in attendance since she reworked her support group to include a potluck dinner, which she sees as culturally appropriate for Black/African-American families.

I deal with low-income and Black people, where family has always been very important, and family in a Black generation is eating. Every Sunday, people come together and eat, and that’s what I use. My support groups are support dinners...I use the food to get them here, and then I train them once I get them here...When they can cook for somebody else that can appreciate it, it makes them feel important (17).

Support groups are a service that Hispanic/Latino caregivers as a group appear to be particularly reluctant to utilize. Because providers believe in the importance of sharing for all caregivers, they have developed techniques specific to this community. Like Black/African-American caregivers, Hispanic/Latino caregivers are responsive to linguistic changes in the way “support group” is described. They are more likely to attend and enjoy a group with a title that is more social, and thus less intimidating, according to one provider.

We find that people tend to go to support groups if it’s not called that. If it’s called “Ladies’ Group” or “Tea Time”, it may be the same format, where they’re just sharing and talking about their deep issues and venting and supporting each other, but it’s not called “Support Group”, and you’ll get 20 women coming together. Whereas, I think people are a little bit intimidated unless they have that [social] connection (46).

Another provider is able to break the ice at her support group by encouraging caregivers to discuss anything on their minds, not just topics that were related to caregiving. This Hispanic/Latino provider works with the fact that every caregiver in the group had been an immigrant.

I think I try to blend culture with our support group, and we talk about how we came to the United States, how we feel, and then they start expressing their feelings, and try to have a solution for everybody. I think the communication with them is very important, because they are able to share everything they have some frustration about in being in another country (47).

The atmosphere in which support groups are conducted can also be important to breaking down barriers. Groups held in a non-institutional setting are more comforting and less likely to have a stigma attached, according to one provider.

Support groups aren’t things that are very common within the Latino culture. But because of the one-on-one trust...they have extremely successful support

groups...These people were placed in [groups] in people's back yards, that had no stigma attached to them (5).

Many providers also found that fun is an important element in attracting more people. Music and a party-like atmosphere are important components of a successful program. A staff member who serves both Black/African-Americans and Hispanic/Latinos describes how she has changed her focus to attract Hispanic/Latino caregivers.

When we do a program for the Latino community, it is more of a festive nature and our other programs seem to be a little more serious, but we did a program last December and it was a dance...We talked about Alzheimer's disease, they ate, played music, and these people paid to come to the program and it was a...holiday party (8).

Another provider agrees, emphasizing the importance of music as an attractor. "You have to be very creative, you must have meals, food, health fair, where the people attend. Music attracts the Latino community" (13).

### ***Addressing Transportation Needs***

Another aspect of program responsiveness is to address transportation needs for the service community. Providers found that they needed to employ creativity to find a way to transport clients. One provider is able to get some of her clients rides through another community agency. "There are other social service agencies that provide transportation, so that those clients who live further distances away, and meet the criteria of the [other] agency, they are able to utilize other transportation services to bring them to and from here" (38). Another provider uses a church's van on weekdays, and has realized an added benefit in giving caregivers slightly more respite time as a result.

We've just now in the last couple of weeks started using another church's van to pick people up on program days. This is just kind of a trial run to test it, but not only does that extend the time that the caregivers have for respite, because we're obviously picking somebody up an hour early so that we're able to pick other people up along the route, so that's extending that time for that caregiver (40).

### **Empowering Clients**

Providers had also identified unclear or incomplete medical diagnoses as a common barrier to use. Empowerment of elders and families was the most common strategy that they used to combat this problem. Rural providers mentioned that many families revered doctors, and accepted their diagnosis without question, even when it lacked specificity. One provider suggests that it is reasonable to get a second opinion. "If their family physician says to them, 'Well it's old age,' then I suggest that they may want a second opinion, and I'll use anecdotal

stories of how somebody thought that's what it was, but in fact [the diagnosis] could change" (21). This tactic often helps families feel justified in seeking answers to their questions.

Like rural residents, Black/African-American elders often did not feel comfortable questioning physicians, and so learned no more than their doctor was willing to volunteer. One provider is trying to change that attitude.

One thing we're trying to work on is trying to empower the folks to stand up for their own rights...On physician visits I always let them know that doctors are just practicing medicine and if you feel uncomfortable that your doctor has told you, it's okay to ask for a second opinion. It's okay to even look for another doctor. Because a lot of times what I have found in the elderly community, and in the African-American community, if they go to doctors, they tend to take the doctor's word as God's word...It's not to be questioned (26).

Empowering Hispanic/Latino families means educating them about Western medical care. However, addressing the issue of folk remedies requires caution on the part of providers. Providers may want to dispel myths about the effectiveness of traditional remedies, but in a manner that does not belittle cultural beliefs. A provider described her approach in trying to convince families not to rely solely on folk remedies. She finds it helpful to demonstrate basic neurology to dissuade them from believing dementia is a curse.

The way I did it was use graphs to show them. Like say for example, I showed them a picture of a person who hadn't been affected by Alzheimer's, and somebody who was, and I say, "These times when you see these sudden mood changes, it's because this is happening in their brain, these chemical changes. So it's not that the person is being possessed, it's just that these chemical imbalances are happening in this person's system, and thereby it's contributing to this type of behavior." And then I would say, "And I really think if you look at that aspect of the person with dementia's care, you would be unwise to keep going to these doctors who are promising the instant cure, because it's not going to happen" (7).

However, another provider urges caution in denying the efficacy of traditional medicine.

We have to understand that we cannot ridicule them, even though the provider may think that medically that's not going to do anything, we have to respect what they believe in. Those are the kinds of things that if we don't respect, then we're not treating that person with the dignity and respect that they need, and they probably are not going to come back (45).

Other Hispanic/Latinos have had bad experiences or are unfamiliar with Western medicine. Although they did not suggest any strategies to assuage these fears, providers do suggest that those agencies who have the means could set up their own clinics where they know care will be

culturally appropriate. For example, Hispanic/Latinos may receive better instruction and feel more comfortable with visiting a Spanish-speaking pharmacy. The same provider finds this effective at her agency.

The comprehensive array of services is designed to meet those needs of people, so that they don't have to go to, say, a pharmacy. After they visit a bilingual provider here, to go to a monolingual pharmacy out in the community someplace who can't speak to them. So we have our own pharmacy (45).

### **Culturally Specific Solutions**

Though primarily a rural issue, isolation can be a challenge in serving caregivers in general. Rural providers commonly deal with transportation barriers due to the disparate populations in rural areas. Lack of transportation can affect caregivers' abilities to attend support group meetings, as well as their ease of taking elders to day care. Providers have worked on variations of the support group idea to facilitate long-distance meetings. One is beginning a support group by phone.

A lot of them can't get out and go to support groups on a regular basis, and we're trying to get a buddy caller program started. What we'll do is connect the caregivers to other caregivers in their area so that every month...they can get a support call saying how are things going (20).

Another provider described her experience producing a caregivers' newsletter. Although it took awhile to gain support, she is now finding that many caregivers like it and take an interest in its content.

Many of them are elderly or they have other family members that they're caring for. We have both groups, children taking care of parents and spouses taking care of spouses, and all with very busy lives...A caregiver newsletter has been very well-received here...Folks are calling me saying, "You know the next time I'd like to see something discussed about activities in the home," or they're dealing with this issue or that issue (21).

The same provider mentions that several day care facilities in her area have developed a program to address the transportation needs that also deals with the difficulties families have in getting elders ready to go out. "The staff will actually go out and help the family get their loved one ready to go to the program...Bathed, and dressed, and out the door, and driven to the day program, again because we don't have the transportation services available for families" (21).

Providers from Hispanic/Latino communities insist that the presence of bilingual staff members is essential for successful service provision. As one provider indicates,

I think definitely the cultural barriers are eased by having bilingual staff or people that at least attempt it... The fact that we provide groups solely in Spanish each day, I think that really makes people feel incorporated into the whole, and like we're investing in everybody and not just trying to mainstream everyone into one type of service (46).

### **Addressing Barriers**

Several themes run through the service modifications that were discussed by providers about clients of different backgrounds. First, almost all caregivers and families benefit from some degree of reassurance that service use does not have to mean relinquishing control of elder care. This is particularly important for providers who work with Black/African-American and Hispanic/Latino families, who often have stronger feelings of familial duty for the provision of care. Second, families of all backgrounds need encouragement from providers to insist on having their questions answered by physicians. Providers view client empowerment as essential to families understanding of dementia and respite care. Due to their clients' lack of familiarity with Western medicine, providers to Hispanic/Latino clients may need to spend more time helping families negotiate the medical system.

Third, all providers' express the need for programs to be responsive to clients' changing needs. This can be accomplished by individualized attention (for rural and Black/African-American clients), or through attention to cultural needs in language, meals, and activities (for Hispanic/Latino elders). Fourth, support groups must be designed to be accessible, and not intimidating, to the target population. This might include long-distance telephone groups in rural areas, or more socially oriented environments to attract Black/African-American and Hispanic/Latino caregivers. Finally, providers to all groups mention the need to work around transportation challenges and financial barriers.

### **RESEARCH QUESTION #7: HOW HAS STAFF HIRING OR TRAINING BEEN MODIFIED TO ADDRESS THE NEEDS OF THE TARGET POPULATION?**

For the most part, the qualities that providers desired in staff members and the ways in which they trained staff were consistent across ethnic lines. Suggestions and caveats offered apply to provision of care for elders with dementia of any ethnicity. A few providers spoke with specificity about serving Black/African-American or Hispanic/Latino clients, and their comments are addressed individually.

## **Shared Views**

### ***Personality***

Providers were nearly unanimous in their agreement that it takes an extraordinary individual to excel at assisting individuals with dementia. A naturally caring personality is high on the list of qualities providers consider essential. One describes this personality trait as a prerequisite.

The primary thing is the caring personality and just knowing how they feel about older people and how they interact with them. There's a lot of skills that you can teach people, but you can't teach somebody to be a caring person. They either are or are not (31).

In addition to empathy, potential staff members need to possess a willingness to become involved with their clients. Providers admit that due to the degenerative nature of Alzheimer's disease, this is sometimes not an easy task. One provider nevertheless feels that it is necessary to forge a strong bond.

You have to pick the right staff, and you have to be willing to give of yourself. For years I taught the nurses' aides, 'Be sure and distance yourself. Don't get too close to these people.' That's a joke. If you're really going to be good at what you do, you have to get involved, you have to get your hands dirty (28).

Another quality that providers consider in hiring decisions is a candidate's knowledge of the community. Due to the financial constraints that often come along with work in the social services, providers look for persons who can not only accurately assess programs' needs, but also know where to look to find resources in the local community and beyond. In the words of one provider, "It definitely has to be somebody who has a good knowledge of the community, a good strong background in social work itself or some type of human service field that knows the needs of people: caregivers, people with Alzheimer's, any kind of caregiving issues, and that knows how to be creative in findings resources that are not there, that's willing to go the extra mile to do whatever it takes to try to give families the information they need" (31).

### ***Volunteers***

Providers consistently lament that caring, knowledgeable individuals are not easy to find, nor to retain. Finding desirable volunteers to work with dementia patients is especially difficult, because these volunteers often must go through extra training. As one provider mentions, "Some of the challenge is getting volunteers ...Especially for the Alzheimer's, to train someone for them to increase their skills in certain things, and what to expect of certain behaviors and attitudes that are displayed by the person that has dementia" (29). In urban areas, logistical problems can combine with personality conflicts to complicate the placement of senior companions. An urban provider finds that,

Not everybody gets along with everybody. So it's really hard to find the combination that the senior companion is satisfied, because she only has to take one bus, and the bus stop is near the home of the patient, and that the caregiver [is satisfied], especially if the patient is in the early stages where he still has command of his senses to make them mutually acceptable [or not] (15).

Finding the right volunteer and making a feasible match with the elder is only the first obstacle. Providers also express difficulty in retaining staff due to the low financial incentive to be employed as an aide. A provider argues that staff shortages are due in large part to low rates of pay for a difficult job.

Nursing assistants go out and do the hardest job there is in the community. They are the link to every one of these clients...and yet they are the lowest paid there is. Like I said, I'm not going to get on my soapbox, I could stay on it for half an hour (35).

The day care providers surveyed seem to have more options in staff than do providers of in-home respite. For example, one day care provider mentions that retirees who already patronize the senior center make the best volunteers.

They plan their whole weekly schedule around the [day care shift] because they have nothing else to do...The van picks them up at home and brings them to the center...So it gives them something to do (32).

### ***Dementia Care Training***

In addition to hiring staff persons and identifying volunteers, providers mention several aspects of dementia care about which they routinely train staff. Many providers mention the importance of patience and consistent service on the part of the workers. Part of this training consists of reinforcing common courtesies that enable families to trust in the agency. A provider lists a few guidelines, "When you talk to them about what you're going to do, you follow through with it...; make sure you have the resources to do so; call when you say the you're going to call; if you're going to be late, let them know that you're going to be late, things like that" (6). Providers also train their staff members to allow extra patience for dementia patients, whose condition sometimes prevents delivery of services as promised. Another provider provides an example of this type of training.

A prime example is a little old farmer out in the community...You send an aide out there for the first time after you have done the assessment...She goes out there and that farmer looks at her and says, 'I ain't taking no bath,' totally refusing to take a bath...Sometimes an aide maybe had to go there three or four times without doing personal care to get in the home and get him used to her. You have to gain the people's trust (35).

One factor that helps staff members deal with the clients' specific needs is knowledge about Alzheimer's disease and dementia. Several providers speak about the importance of educating their work staff. "I think the most important thing is providing education to the professional, and equipping them with the tools and resources prior to contact with the client. If the [client] comes to you and you don't know anything, they're very unlikely to go to another professional who might know something" (7). In addition to being able to inform the clients, staff members with some knowledge of dementia will be better able to deal with or even preempt problematic behaviors. A day care provider observes,

Particularly [with] people with moderate to advanced dementia, a lot of what they're picking up on are more subtle cues or body language and tone of voice, and I think if you have anger in the room or people responding with anger, they pick up on that and get somewhat agitated. But if the staff member is skillful and [can] deal with it and deescalate it, and sort of calms the environment down then it only has temporary negative effects on the room (26).

Although providers cite the need to train staff to expect behavioral changes, most also train them to treat demented elders with respect. One provider is adamant about preserving the dignity of elders.

My program is teaching. I tell my volunteers, 'Do not ever treat anyone like they're not adults. Do not talk to them like they're a child. Always let them be an adult, because when they lose their dignity, that's when they get hostile' (17).

A related idea is that elders should be addressed as if they are cogent individuals, regardless of their true mental state. The same provider urges her staff to obey a sort of Golden Rule with the patients.

I also tell them that when you're talking to them, you don't talk to them in the third person, you talk to them one-on-one, conversation between you and them. When you want them to do something, you talk **to** them, not **around** them...You treat them the way you want to be treated, even though they may have this disease (17).

Several providers describe staff supervision and training policies that have worked for them. One recommends setting up a system of rewards for aides who are particularly effective. At her agency, they award "special recognition for the aide that goes that extra mile, [because] you do have special aides that will just continually hang in there" (35). Another provider suggests that agencies hold periodic team meetings in which challenging cases are discussed. In her experience, "We'd bring up this difficult case and what would you suggest, because sometimes other people's suggestions might help, or they may have had the same experience and found the key to helping or breaking that barrier" (4).

### **Cultural Issues**

A few providers within Black/African-American and Hispanic/Latino communities mentioned some staff issues that are specific to their clients' ethnicity.

#### ***Black/African-American Cultural Issues***

A common focus for providers who work with Black/African-American elders, especially in the South, is showing respect by use of titles. One holds this to be particularly important with the older clients.

The better I get to know them, if they are younger, then we may use first names. But the older ones, I would never. The patients out in the day care, they are not Mary, they are Ms. Mary or Mr. So-and-so. Everybody here is there to be respectful of these people (14).

Another provider allows her staff to address elders informally only after receiving their permission. "I tell them, 'It's Mr. or Miss. If they tell you it's Juanita, then you call them that. They'll let you know'" (17).

Other areas in which staff persons are trained before working with Black/African-American clients deal with religious and cultural diversity. Because religion plays an important role in the lives of many of her aides, one provider feels the need to caution her staff from imposing on clients who do not share their faith.

We have to really caution our aides not to put too much religion into what they do unless the client is initiating it in some way or it seems appropriate to the client, because for a lot of our aides, that is their life and that's what they're going to put into their work, and for some of our clients that might not be appropriate (12).

Another provider points out the need for staff training in cultural diversity, even in geographic areas in which staff and clients are often of the same ethnicity.

I've led some classes on cultural diversity...It can be something that's taught. Nobody is going to come into this being all knowing including people who are right here in the African-American community (8).

#### ***Hispanic/Latino Cultural Issues***

Providers who speak specifically about staffing for Hispanic/Latino clients put more emphasis on hiring than on training of staff. Several mention the importance of hiring staff persons who will seem familiar and comfortable to the clients. One provider describes her agency's rationale for hiring mostly Hispanic/Latino staff.

Basically what it comes down to, whenever you would have a client call in for possible services or you'd go to their home, they saw comfort the minute they saw you, the

minute they spoke to you. If they told you that they use this herb or this tea, you knew about it. If they told you they prayed to a saint, you knew about it. If they said they had a holiday coming up, you knew about it. There was no strange ground.

To this provider and others, a staff person's understanding of the Hispanic/Latino culture is a necessary prerequisite onto which other skills can be built.

### **Staff Hiring and Training Issues**

In general, providers within the three cultural groups studied here had similar advice for hiring and training of quality staff members. All providers recognized the importance of recruiting caring and involved staff members. It was also agreed that knowledge of the service community was very important. Providers believed that besides education about Alzheimer's disease, staff members should receive training in the importance of patience and consistency when working with dementia clients. Because of the specific challenges associated with dementia clientele, workers should be taught about the expected behavior changes and the appropriate communication techniques for the care setting. In addition to the aforementioned strategies, the Black/African American providers also include the importance of teaching staff to address the clients respectfully using their title. There is consensus among the Hispanic/Latino respite providers that the most effective staff members are often those hired from the same ethnic community as the service population.

### **RESEARCH QUESTION #8: WHAT ARE THE KEY COMPONENTS TO SUCCESSFULLY PROVIDE RESPITE SERVICES TO THE TARGET POPULATION?**

The providers identified key components that lead to successful service programs. Some factors, such as knowledge of the service community, assist with the development and targeting of services. Other components--developing a relationship built on trust, setting clear expectations, following through--are essential in maintaining clients' perceptions of appropriate service. Providers to rural, Black/African-American, and Hispanic/Latino clients shared their views of the most important factors to serving their community.

## **Rural Areas**

### ***Knowing the Community***

Providers who serve mostly-White rural communities stress the need to make community members aware of respite services, and then working to gain their trust. Providers feel that the process begins with attaining knowledge about the characteristics of the specific community. Knowledge of the demographic characteristics of the population that will most likely utilize services enables providers to do selective outreach and tailor programs to match community needs. In more racially homogeneous areas, providers would be interested in such characteristics as level of education and community tenure. One provider describes the cultural characteristics she considers relevant to care.

To know the community, for one. The history is also important. If people are able to read in that area, what grade level would be a majority of your people. Where did they come from...That kind of stuff, because then you're bringing in cultural [issues] (27).

Once a provider determines the population mixture with which she will be working, she can begin to formulate an idea of the specific services that will be needed. Providers in rural areas emphasize the need to spread awareness of a program's offerings. Because populations are often geographically diffuse, staff members need to go out into the community to do outreach, rather than waiting to be discovered by caregivers in need. One provider suggests,

Get the information out there in some way or another...because if you don't know about something you're not necessarily going to look for it if you don't know it's there. So you have to go to them and you have to let them know that you're there (20).

Thus, building a citizen base that is aware of a program's existence is one essential key to providing service.

### ***Building and Earning Trust***

Perhaps more important to the providers interviewed is what happens once a family begins to receive services. After a caregiver takes the first step of inquiring about respite services, it is up to the provider to build on that initial trust. Providers mention several aspects of earning and maintaining trust. The first is simply listening to families, and making clear the intention to help. According to one provider,

I think the most important thing is to be there for them. To let them know that you really care and that you're interested in trying to help them to make their lives better. To make their life easier, make the burden a little easier to bear (34).

Part of this supportive role involves striking a balance between educating families about services and allowing them to make their own decisions. Another provider finds that, for services to be effective, families must feel ready for them.

Being there when it's needed...or when they feel that it's needed. As professionals we sometimes think it's needed now, let's get started. But I found our families don't think that way...and absolutely, it is up to them (19).

Another important part of building trust is creating consistent relationships between providers and families of care recipients. Being honest and keeping one's word is considered essential by many providers. One says that to gain trust,

It takes calling them back when you're telling them you're going to. If you tell them you're going to do a home visit next week, you be there for that home visit. Standing up to your word I think is the biggest thing that you can do for your community (35).

If families can count on a provider to back up claims with action, they will be satisfied.

Continuity in staffing can also help ensure trust, particularly for in-home respite agencies. One provider of in-home care gives an example of the importance of a one-on-one relationship to effective care.

I just went to this lady's house on Friday...and she said, 'Now will I ever see you again?'...I think the agencies are such that somebody comes in and does an evaluation, you never see them again, and another comes. They [families] have no idea who everybody is who's in and out...I think people just need to know at least one name and number of someone that they know is there (23).

Repeatedly visiting the same communities can be beneficial not only to families but also to providers. With each visit to a community comes greater familiarity, and thus more trust. A provider describes this pattern.

They have seen you in the community. They know who you are. They know why you're in the community, so when you pull up, the people next door are going to know who you are. That's when it works. When you get to the point that they know who you are and you are there to help them and they believe that's why you're there, you've got it made then (35).

In short, providers from rural service areas agree that an essential element of effective programs include developing relationships with service recipients that revolve around trust, support, and consistency. A successful program is also one whose care providers have

knowledge and insight about the community they serve. Diligent efforts toward outreach are critical, especially given the geographic distance required to contact potential clients.

### **Black/African-American Communities**

Providers who serve primarily Black/African-American clients perceive similar components of successful service, but use different strategies for developing services in their target communities.

#### ***Gaining Awareness of Community Resources***

The value of knowing the characteristics of the community is more strongly stated by Black/African-American providers than by rural providers. For example, the socioeconomic status of a community has an impact on the funding mechanisms a provider can employ to make services available. One provider discusses some of the questions that providers should ask themselves and others about their community.

[Providers] need to be sensitive to language, to cultural preferences, and they have to be aware of the socioeconomic barriers in their community. Is it a wealthy community? Is it a financially impoverished community? What types of benefits are available through the state and the county to help people who are financially challenged? They have to have a full picture of what resources are available in the community (11).

Another provider affirms the need to be aware of community resources. "They need to know the resources that exist within their community, because you need the support of other resources in your community (38).

#### ***Knowing Cultural Characteristics***

Knowledge of ethnicity and cultural backgrounds was another often cited prerequisite to molding successful care programs. A Southern provider explains, "I think to understand the culture of the people, to understand their background, because what kinds of activities that you have for clients has to do with what is their background" (38). She provides an example of an unusual day care activity, riding a city bus, that illustrates the way in which knowledge of culture can improve a program's responsiveness.

The idea of riding a city bus may be something that you do not incorporate into some other population, but understanding that coming from a Southern African-American background, the culture is people-oriented, people interactive. So...we provide opportunities to keep them in the community, which is the norm for them, rather than bringing them to a facility and keeping them here for five hours (38).

Knowledge of core community values can act as a base from which to create options that work better for clients. Another provider suggests a steering committee that reflects the ethnic composition of the community as an effective way to uncover these values.

[A service provider] might have to form a committee of community providers in each of the indigenous communities in their area...[made up of] some members of the aging services network in that community who represent a variety of different cultural and ethnic backgrounds so that there could be input on what's appropriate (11).

Providers also mention the need for individualized knowledge about clients and their families before making a care plan. A physical assessment is obviously necessary, but providers also believe in assessing the knowledge base of caregivers. As one provider put it, "I think it's really important that we put what we know and don't know on the line to give them an opportunity to put what they know and don't know on the line" (39). Family structure and family dynamics can also play a part in managing respite care. Another provider states,

Family dynamics are something that we do discuss when we get together as providers. Who is involved in the care, who's not involved in the care, how many children, who is the caregiver out of the 13 children...And it does matter if it's a child caregiver, rather than a spouse caregiver. There are different situations that certainly make a difference in how you approach the care situation (37).

### ***Targeting Outreach Efforts***

Outreach provides an opportunity to act on the information that providers have gleaned about the community. Providers who serve Black/African-American communities feel that a successful outreach program should have several characteristics. If printed materials are to be used, one provider urges that they be designed appropriately for the culture.

You need to make sure that whatever outreach materials that you have are culturally sensitive...We recently did our brochure over again. It's a patchwork of different faces, not just showing one race, because for some people they, because they don't know about the disease, they may have a thought that Alzheimer's only affects Whites or Blacks (8).

However, another provider doubts the effectiveness of print media, preferring to talk with families in person. "In terms of African-Americans, word of mouth is a very effective mechanism for recruitment, rather than printing a lot of literature with a whole lot of written stuff that nobody

is going to read” (38). One provider finds that knowledge of the churches that potential clients attend helps her with outreach to Black/African-American populations.

If we're able to get the pastors and some of the administrative people in the churches to even come out and see our program, introduce the program [to] them, then they can pass that information on to the congregation. The church is one of the major supports for the African-American community (26).

### ***Building Community Trust***

Trust building is a component of effective service that goes hand in hand with targeted outreach. Several providers discuss the importance of collaboration with established community leaders in establishing an initial level of trust. A provider elaborates, “When you have a key [community] person who can help you, then nine times out of ten, they have already gained that trust in the community, so they can be like your sponsor who can introduce you to the other folks. And then it can kind of go from there” (26). Having come to the same conclusion, another provider describes an example of an effective “sponsor” in a close-knit Black/African-American community.

One of the ways they went about doing that, to actually get out into the communities, is they recruited a black sorority that's a real established sorority of older women that are in the area...So it works better if you identify a group or some people in the community itself that can actually do or present what you're trying to get across...You can't just go in by yourself and say, 'I'm here,' because there is some resistance if you're an outsider, whether it's age or race or culture or religion. You have to know how to go in (37).

Another element of successful service is maintaining a relationship of trust between clients and workers. This can be accomplished by being honest with families about the services that may be provided, according to one provider.

I think by being honest and up-front. You tell them what you can't do as well as what you can do. You give them what help you know about, but you don't promise things that you don't know (39).

In addition to being realistic, providers find it important to give clients and families a high degree of respect. Another provider thinks this is especially true for Black/African-American elders.

I think it is very important to show these people respect. So many times in their lives, they've not been respected. And I think they appreciate it when you do show them respect, and they deserve it! (14).

### ***Summary***

As with the rural providers, Black/African American respite providers echoed the importance of community knowledge as an important component of program success. Understanding the

socio-economic status of the community members was targeted as being of special importance. Along the same lines, program developers should have awareness of the cultural aspects of those they serve, both individually and collectively. Outreach to Black/African American clients is multifaceted, achieved by culturally appropriate written material and through personal interactions. Finally, providers serving Black/African-Americans agree that gaining trust within the community is a key condition to successful programming. One unique way to achieve the trust within this ethnic group is by soliciting the support and collaboration from respected community leaders.

### **Hispanic/Latino Families**

Diverse populations often have unique characteristics that make the development of appropriate services challenging. In many areas of the United States, Hispanic/Latino respite programs have been tailored to assist families caring for elders with dementia more adequately.

#### ***Understanding Community Language and Culture***

Overwhelmingly, the staff responsible for the initiation and provision of services to Hispanic/Latino families of diverse nationalities report the need to know and understand the community to be served as a key element in effective service delivery. One individual providing care to Hispanic/Latino clients summarizes the need to know the community by saying simply, "Find out about your population...To know the community. To know who needs services and what's here and what's lacking" (3).

More specifically, there is an overwhelming need to address the language barriers present when serving a Hispanic/Latino community. One agency worker says simply, "I think the most important thing is to have a person as a staff person who is from the community and speaks the language" (50). This necessitates not only utilizing bilingual staff, but using appropriate written materials and media advertising. One staff member identifies communication as the foundation of service development:

Definitely the first thing that you would need in place as far as I could think would be an outreach worker who is fluent, very fluent in both languages. Not only the spoken, but the written because there's a lot of translation in the written word also (44).

Providers also recognize that even within Hispanic/Latino communities there can be diversity that should be addressed. When speaking of the level of Spanish translation required to meet these needs, a provider asks,

What level is high enough, what level is too high? Do we use Castilian Spanish? That would be ridiculous. But, you know if we use Spanish that is too slangy, will we offend some people? Are we using words that are used in Mexico but not in El Salvador? That's really hard (5).

While it is agreed that common language is important in developing services targeted to this population, understanding the community goes beyond the language issue. Language is a significant, but not the only, element relevant to creating services that Hispanic/Latino recipients will use. The culture needs to be acknowledged holistically in order to understand the family appropriately. For families in a particular community the provider should "know what their culture is and how they handle [issues], how they view illness in the family and who is responsible for their care"(42).

### ***Learning About Community Cultures***

Country of origin and length of time in the United States can also impact how services should be rendered, since both influence the acculturation level in a community. One service provider in California summarizes:

You know, are you dealing with a population who have been in the United States for four generations? That's a very different outreach pattern than you are dealing with [in] a population which is a recent immigrant (5).

The same provider also speaks about the unique origins of families across different Hispanic/Latino communities. She emphasizes the need for accurate assessment of the target population. When speaking about the differences in providing services for Latinos of Mexican descent she states,

Now if you were working, let's say, in Miami, you might be working with people who are of Cuban descent, or perhaps South American decent. There are language differences, there is a difference in that community's history in the country, there are acculturation differences, and there are socioeconomic differences and educational differences that really, really, really, come into play (5).

One strategy for obtaining staff people with the unique cultural knowledge required to serve the community effectively is by seeking out persons from the community itself. These community individuals may be able to serve as actual staff members or as advisors on boards or committees. A provider explains how both community leaders and caregivers aide in the recruitment and support of new clients.

[Key leaders] help to reach the Latino community, they give you information how to reach them and I also have caregivers, they bring ideas and activities and they talk to people who have Alzheimer's or memory problems, so what I have is community leaders, caregivers...to help in the committee (13).

Another service provider is able to summarize the significance of culturally appropriate services and staff members by cautioning against "...taking someone from an Hispanic background and an Hispanic culture and popping them into your American idea and saying...fit in" (44).

Another issue, which relates to the ability of an agency to effectively provide services, is the awareness of the socioeconomic status of the clientele. Providers sometimes find that residents of particular areas share a similar income range and standard of living. In many respects, these characteristics can transcend ethnic cultures, providing a common experience for all residents that must be addressed by service providers in order to deliver care effectively. Public financial resources may be available for those that qualify. One provider suggests that knowledge about the community can make a financial difference. "If you are working in the lower income areas, then this population may qualify for in-home supportive services, Medicaid, SSI, things like that" (6).

### ***Raising Awareness and Building Trust***

In addition to the development of appropriate services, the ability to reach potential clients can be a serious challenge in some communities. Many providers discuss the importance of finding ways to notify individuals in need of the services. Taking advantage of other institutions that are already established in the community offers service agencies a way to communicate offerings to the targeted group, and helps them gain credibility with the clients. One staff member reports the effectiveness of outreach by identifying the places frequented by potential service recipients.

...and they did intensive outreach, bringing clients to the door through the Spanish Mexican restaurants and through the Spanish radio and some Spanish newspapers in the areas and the Spanish focused grocery stores and it was amazing (43).

The issue of trust repeatedly occurs as respite providers explain the important elements of successful services. There are several key components in the process of developing trust, one of which is respect. One provider reports that respect is critical to creating a trusting environment, particularly, "...respect for this culture that you are interacting with...That definitely helps establish trust" (44). A trusting relationship does not always occur quickly, but respect can be demonstrated over time. "They are not going to want to put their trust in someone who isn't

showing them that they can be trusted” (44). Another staff member describes the importance of respect and the lack of trust observed in some instances,

...this is a basic tenet of customer care, is to treat people with dignity. Truly you find so many people who are humble people, and they're treated with such disrespect simply because they look different, their health is poor, they can't speak the language. That's not the case with our organization...(45).

Honesty is another essential antecedent to establishing a trusting relationship with clients. One staff member speaks about honesty in this way, “Just be open and honest with them. Tell them what you can do and what you can't do”(3). Another provider echoes the importance of honesty:

I think keeping your word. If they come to you, and you tell them that you're going to hook them up with a support group, keeping your promise and giving them that resource (support group) as soon as possible. Or if you don't have access to that, just being honest with them...(7).

As with the other providers, Hispanic/Latino respite providers echoed the importance of community knowledge as an important component of program success. Given the diversity of this population the value of such cultural knowledge of language, beliefs, protocols, and more of each nationality cannot be overstressed. Additionally, the issue of language diversity must be addressed. As with other groups, building relationships based in honesty and respect are also crucial elements in developing successful programs.

### **Key Strategies**

Providers, from all communities, agreed upon certain common requirements for creating quality programs. Each group recognized the importance of developing services that are understanding of and sensitive to the culture and characteristics of the target community. Staff members capable of communicating in the same language as the care recipients are fundamental to the success of culturally diverse respite programs.

In rural areas, providers stressed the importance of building awareness of respite programs among their communities. Relationships with clients need to be built on trust, support, and consistency. Also, providers need to understand their areas as well as the cultural preferences of their community. Similarly, providers within Black/African-American communities also confirm the need to be aware of their communities and the other resources that may be available for

caregivers. These staff members also see the importance of building trust. They suggest working with key community leaders. Additionally, providers in Black/African-American communities stress that cultural appropriateness of materials and personal interactions is vital to these families as well. Providers targeting Hispanic/Latino elders echo analogous sentiments. In addition to needed outreach and community education, building trust, creating clear expectations, consistency in service delivery, these providers stress cultural and language issues. Specifically, providers in Hispanic/Latino communities emphasize the significance of understanding the diversity of both culture and language within this multi-ethnic population.

## **SUCCESSFULLY DELIVERING RESPITE SERVICES TO DIVERSE POPULATIONS**

Demonstration providers have offered the benefit of their experiences in successfully serving diverse populations. Many have noted specific strategies for outreach and service development. Others have explained key cultural issues necessary for understanding the beliefs and needs of their target populations.

The earlier Research Question sections have facilitated a broad discussion of some of the essential service delivery topics providers have identified and addressed. The following section will summarize the important issues by cultural group.

### **Serving Rural Communities**

Providers in rural communities stress the importance of understanding that these areas do have their own geographic culture. In general, rural individuals are relatively isolated and have fewer opportunities for education, medical care, and other services. There is a tendency to rely on oneself, one's family, and one's church. The relationship to family and church are very strong and central within rural communities.

Perhaps because of the size of the communities, there is an enhanced level of familiarity among residents. Even though rural areas are more homogeneous than many urban areas, discrimination does still exist—sometimes based on race, other times based in “outsiderness”. There is a distrust of outsiders, including service staff, service agencies, researchers, and government institutions.

***Views of Alzheimer's Disease***

Alzheimer's disease is most often seen as mental illness or as normal aging. Families commonly respond with denial, fear, and embarrassment when their elders exhibit dementia symptoms. Specifically, in rural areas there is a lack of general knowledge and understanding of Alzheimer's disease. As there are few informational resources, most families are dependent upon their family doctors for dementia specifics. Unfortunately, rural physicians, especially those who have been practicing for a number of years, have little training in Alzheimer's disease and the possible treatments.

***Views of Support Services***

Most providers found a general lack of understanding of just what "respite" is and a limited appreciation of the value of dementia-specific services among their clientele. These observations were not limited to rural areas. Providers within rural communities, like their urban and ethnic counterparts, faced the prevalent notion that family care is better than professional or paid care because of the emotional ties of the familial relationship. Families of all cultural groups expressed guilt at using services, embarrassment about the behavioral symptoms of Alzheimer's disease, as well as anxiety and trust issues in letting someone else provide care. Providers also reported that younger caregivers, regardless of their family relationship or ethnicity, were more receptive to service use than older caregivers.

In rural areas and especially with less educated families, providers had to address the stigma that support services are a form of welfare or a public handout. There is also a general distrust of the government and of any service programs that are affiliated with government programs.

***Staff Issues***

Rural clients prefer staff members of similar ethnic backgrounds and to be familiar members of the community. Religious affiliation and similar gender (i.e., male attendants for male care recipients) are also important in establishing comfortable service provision. However, providers have found that the value of respite to caregivers can outweigh other issues. Once families believe that services are of high quality and beneficial, they are less concerned about the ethnicity and background of the person delivering them.

Retaining good aides is a challenge even in rural areas where other employment opportunities may not be as plentiful. Providers recommend using some form of recognition and reward for those aides that excel. Team meetings that build team support and allow for aides to provide

input into the care plan were also seen to be helpful in promoting quality care and enhancing staff moral.

***Identifying and Addressing Barriers to Service***

For those providing services in rural locations, transportation, cost and funding, and agency staffing difficulties are among the most common barriers to service usage. Additionally, lack of physician understanding and referral plus a fear of bureaucracy by the potential clients are frequent dilemmas. Rural residents also have a belief system that values independence.

Many rural barriers can be addressed through innovation and responsiveness to client needs. For example, due to rural families' desire for self-sufficiency, they may view assistance as a relinquishment of their responsibilities, or a government handout. Providers can address this when approaching caregivers by emphasizing that respite care is complementary to, rather than a replacement of, family care. Providers can also attend to the concern that respite is a handout by charging a nominal fee for the services. Additionally, providers can focus on empowering families within their relationships with their physicians in order to address the lack of a diagnosis or medical explanations.

The small size of most rural agencies allows providers to address challenges by individualizing care plans. Program responsiveness (such as matching clients with familiar aides) can be crucial in developing services with which families can be comfortable. Finally, rural providers need to be creative in devising solutions to the barriers bred by isolation. Examples include long-distance support groups and information newsletters, as well as more extensive transportation networks.

***Essential Elements of Effective Respite Programs***

Providers from rural service areas agree that an essential element of effective programs include developing relationships with service recipients that revolve around trust, support, and consistency. A successful program is also one whose care providers have knowledge and insight about the community they serve. Diligent outreach efforts are critical, especially given the geographic distance required to contact potential clients.

### **Serving Black/African-American Communities**

Black/African-American communities are recognized for their strong sense of extended family and community ties. This community has a greater prevalence of working caregivers, primary caregivers who are more distant relatives, and wider family involvement in caregiving. However, providers note, there is still usually just one person that bears primary responsibility for caregiving, and simply receives input from others.

Black/African-Americans, like their rural White peers, possess great pride in their ability to remain self-sufficient and “take care of their own”. They also share a pervasive mistrust of government assistance and the medical system. Spirituality and organized religion also has an important role, both to the Black/African-American community in general, and as a support structure for individual caregivers. The concept of respect among community members is also highly valued, due to past injustices.

### ***Views of Alzheimer’s Disease***

In Black/African-American communities, providers note that families seem to take the challenge of Alzheimer’s disease in stride and are more realistic in dealing with the related care tasks. Additionally, this community shares the mistaken belief that the behavioral symptoms are signs of “craziness” or other mental illnesses. Other times, families will assume that the dementia symptoms are natural for an older person and thus, deny the need to seek medical attention or other resources.

### ***Views of Support Services***

Though no unique views of support services were identified for the Black/African-American community, they do share a general lack of understanding of just what “respite” is and a limited appreciation of the value of dementia-specific services for their elders. Black/African-Americans often believe that family care is better than professional or paid care because of the familial relationship. Like other families, Black/African-Americans feel guilty about using services and embarrassed about the behavior symptoms of Alzheimer’s disease, as well as express anxiety about letting someone else provide care. Providers also observe that younger caregivers were more receptive to service use than older caregivers.

This community is also sensitive to the view of support services as a form of welfare or a public handout. However, this was more pronounced among less educated families. There is also a pervasive distrust of the research community and government programs.

***Staff Issues***

Overall, members of the Black/African-American community express feelings of initial reluctance to accept a White care provider. This reluctance is related to mistrust and social mores that have been ingrained for generations. However, participation in the respite programs with individuals of diverse backgrounds often facilitated understanding and trust in the multiracial settings.

Providers within the Black/African-American communities recognize the importance of recruiting caring and involved staff members who are familiar with the service community. Providers believed that besides education about Alzheimer's disease, staff members should receive training in the importance of patience and consistency when working with dementia clients. Because of the specific challenges associated with dementia clientele, workers should be taught about the expected behavioral changes and the appropriate communication techniques for the care setting. In addition, the Black/African American providers also include the importance of teaching staff to address the clients respectfully as Mister or Misses.

Recognizing and rewarding exemplary work by agency staff and team meetings have been seen to enhance staff retention.

***Identifying and Addressing Barriers to Service***

Providers within the Black/African American communities face structural barriers to providing services: scarce funding, distrust of government services, and suspicion of the medical research community. Additionally, it is often difficult to locate and educate caregivers due to the pervasive denial or delay in seeking services that takes place.

Providers who serve Black/African-American clientele have found ways to make services more effective for their target populations. Respite services are discussed in terms of supplementing, not replacing, family care. Since Black/African-American families often want to keep care within the family, providers work to provide services in a friendly, home-like manner that does not

suggest institutionalization. Providers rely on familiar activities, often based in music or religion. Programs with social names, like “club”, are more likely to be accepted by the community.

Support groups can be better received by combining them with a potluck dinner or luncheon. Providers can also individualize services to better meet caregivers’ needs. The prevalence of working caregivers in the Black/African-American community has led some providers to conduct seminars within large workplaces, or to extend day care hours to accommodate busy schedules.

### ***Essential Elements of Effective Respite Programs***

Providers within Black/African American neighborhoods stress the importance of understanding their community in developing appropriate services. Understanding the socio-economic status and needs of the community members was targeted as being of special importance. Along the same lines, program developers should have awareness of the cultural aspects of those they serve, both individually and collectively. Specifically, outreach materials and interactions need to be culturally sensitive and tailored to the targeted population. Most important may be the need to gain trust within the community as a key condition to successful programming. A suggested way to achieve the trust within this ethnic group is by soliciting the support and collaboration from respected community leaders.

### **Serving Hispanic/Latino Communities**

Providers within the Hispanic/Latino communities acknowledge the wide diversity within this population of many nationalities. The term “Hispanic/Latino” represents a great variety in cultures, dialects, and etiquette. Of particular importance is for providers to gain a cultural awareness, as well as language knowledge, of the community that they seek to serve. When possible, programs that “mirror” their target population are often most able to adequately provide respite.

Despite the diversity in cultural norms within the Hispanic/Latino community, each nationality places a very strong reliance on the family unit to solve problems and provide care. Gestures of respect are considered important, and differ by group within the culture. Many clients are monolingual Spanish-speakers with relatively low levels of literacy, which results in isolation from mainstream services, and a greater valuation of one-on-one relationships with service providers.

### ***Views of Alzheimer's Disease***

Hispanic/Latinos, like the other groups included in this research, often believe that Alzheimer's disease is a form of mental illness or insanity. Additionally, they may conceive of dementia as a "curse" or a punishment for previous "bad" behavior. Other responses include religious explanations: the caregivers' cross to bear; or the elder's possession by evil spirits. Believing in curses, punishment, and possession leads individuals to seek non-medical cures. Similar to families of other cultures, Hispanic/Latino family members react with denial, fear, and embarrassment.

### ***Views of Support Services***

Agency staff in Hispanic/Latino communities mentioned that their clients' perceptions of support services and government programs had been shaped by their experiences in their former country. This results in mistrust of government services in the United States. There is also a stigma that support services are a form of welfare or a public handout in this community. Additionally, as many of these families are monolingual Spanish speakers, this language barrier inhibits their awareness of information and traditional support services as well as their ability to access them.

Like other communities, Hispanic/Latino families have a general lack of understanding of just what "respite" is and a limited appreciation of the value of dementia-specific services. There is also a strong preference for family care over professional or paid care because of the emotional component. Hispanic/Latino families expressed guilt at using services, embarrassment about the behavior symptoms of Alzheimer's disease, as well as anxiety and trust issues in letting someone else provide care. Providers also reported that younger caregivers were more receptive to service use than older caregivers.

### ***Staff Issues***

Bicultural staff members enhance the comfort level of Hispanic/Latino families. This refers to a familiarity with the community, the clients' nationalities, and speaking Spanish. There is consensus among the Hispanic/Latino respite providers that the most effective staff members are those hired from the same ethnic community. Most importantly, providers' stress in hiring and training staff members, it is important to recognize the diversity within the Hispanic/Latino community: nationalities, linguistic differences, socio-economic levels, amount of education and degree of acculturation. Additionally, providers agree on the value of recognizing and rewarding

staff members for their skill and expertise. Providers also see merit in regular team meetings to build team support and morale as well as to give all staff members an opportunity to have input.

In general, providers within the three cultural groups under study had similar advice on hiring and training of quality staff members. All providers recognized the importance of recruiting caring and involved staff members with knowledge of the service community. Training should include education about Alzheimer's disease, the importance of patience and consistency when working with dementia clients, difficult behaviors, and respectful communication techniques for the care setting.

***Identifying and Addressing Barriers to Service***

Providers within the Hispanic/Latino populations identify the strong cultural value of family caregiving, a pervasive mistrust for the government, a preference for folk or home remedies, and difficulties maneuvering through complex bureaucracies as barriers faced by these communities. Additionally, many Hispanic/Latino families do not value Western medical treatments and if they do seek care from a physician, they are often not diagnosed appropriately. In every setting, language represents a significant barrier to service use for this group.

Providers have developed techniques to address resistance to service use that are specific to the Hispanic/Latino culture. At the initial encounter with a family, providers reassure families both that they are not alone in dealing with dementia, and that seeking assistance should not be considered selfish or neglectful of familial duties. Providers also try gently to dispel myths about the effectiveness of folk medicine, without insulting these traditional beliefs. They address other institutional barriers to use, such as mistrust of bureaucracy, by providing assistance with filling out forms and applications, and helping families negotiate the system.

Providers also tailor the services, the materials, and their personal interactions to be appropriate to the Hispanic/Latino cultures. Services must be bilingual, and preferably with bicultural staff members. Providers find it helpful to offer traditional food, and to celebrate national holidays of their clients' home countries. Additionally, providers develop service activities around social themes in non-institutional settings. Support groups are referred to as "clubs" or "tea-time".

### ***Essential Elements of Effective Respite Programs***

As with the other providers, Hispanic/Latino respite providers echoed the importance of community knowledge as a key component of program success. Specifically, providers in Hispanic/Latino communities emphasize the significance of understanding the diversity of both culture and language within this population of many nationalities.

Providers targeting Hispanic/Latino elders stress the importance of developing culturally appropriate materials and activities. In addition to needed outreach and community education about Alzheimer's disease and respite services available, building trust, creating clear expectations, consistency in service delivery, are significant. However, language and cultural issues remain core components of a successful program.

## **IMPLICATIONS FOR SERVICE PROVISION**

Providers from the ADDGS project have offered specific and detailed advice for those who wish to develop acceptable and appropriate services for diverse populations. It is clear from the interviews, that each provider has a wealth of experience to share about their service communities. Yet, in spite of the diversity of these populations, several general recommendations can be identified that are pertinent to all families and areas.

### **General Lessons for Service Delivery**

- Become familiar with your service community!
  - Get to know both the culture and language of the community.
  - Become aware of other available resources and services.
  - Understand the issues related to service use, such as socio-economic levels, education, employment status, and other key factors.
  - Understand family structures and caregiving beliefs.
- Develop Appropriate and Responsive Service Programs!
  - Use culturally appropriate materials and activities.
  - Hire and train bicultural staff members (from the community if possible).
  - Individualize care plans when possible.
  - Match hours available to caregiver needs.
  - Create homelike environment with friendly, welcoming staff.
  - Use "socializing" context for support groups.
  - Use "sliding fees" to negate "welfare" stigma.
- Build trusting relationships!
  - Stress honesty in interactions.
  - Create clear expectations for care with clients.
  - Follow through! Follow through! Follow through!

- Recognize and reward excellent staff members.
  - Hold Team meetings so all staff members can provide input.
- Educate the Community!
  - Provide information about Alzheimer's disease.
  - Let families know about the purpose and availability of respite services.
  - Explain the value of dementia-specific services.
  - Inform how support services can enhance family care.

Providers also shared issues and advice unique to specific cultural groups. These service aspects, they are quick to add, are second to developing a caring, compassionate service. Understanding the community and building trusting relationships can overcome differences. However, special attention to some of the unique needs of the various cultures can smooth the transition for new service users and ensure greater satisfaction of all users. Providers offered the following lessons.

### **Lessons for Rural Communities**

- Creativity, flexibility, and innovation are needed to address isolation, transportation needs, and lack of resources.
- Respite should be promoted as an support for, not a replacement of, family care.
- Charging a small fee can address the welfare or handout stigma.
- Focus on empowering clients in their relationships with medical professionals.
- Assign familiar aides to families when possible.

### **Lessons for Black/African-American Communities**

- Work with key community leaders to develop trust with residents.
- Address the needs of working caregivers.
- Promote respite as an aid to, not replacement of, family care.
- Create a social atmosphere, preferably with food.
- Match workers and clients by race when possible.

### **Lessons for Hispanic/Latino Communities**

- Develop bicultural expertise in staffing.
  - Mirror the community, ethnically and culturally when possible.
- Incorporate folk medicine into educational approaches.
- Educate about the medical aspects of Alzheimer's disease.
- Providing familiar food and activities can create more comfortable environments.
- Reassure caregivers that they are not alone.
- Assure caregivers that using respite is not selfish or neglectful.
- Create social, friendly environments for service provision.

**ENDNOTE**

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<sup>1</sup> Each interviewee is referred to by a numeric code to ensure confidentiality of their responses.

# CONCLUSION

## CONCLUSION

This set of related studies was undertaken with the knowledge that most service providers believe respite programs are both desired by, and useful for, families caring for persons afflicted with Alzheimer's disease. The focus has been on the manner in which a diverse population of caregiving families used respite services, the beliefs of these families about caregiving and their preferences for services. The intent was not to determine the outcomes of respite program for clients, but to profile the patterns of respite use that occur when services are made available in a culturally appropriate manner and at a reasonable cost to families in their own communities.

This report includes a large number of findings regarding behaviors and preferences of family members who provide care for their relatives have been reported. To capture more fully the utility of these findings for policy, the results of this work are summarized and discussed here under four major themes. In the final section, six implications for practice are delineated to facilitate the translation of this research into practice.

### 1. CULTURE AND DIVERSITY OF CAREGIVING CONTEXTS

*There is great diversity among caregivers in the contexts within which they provide care and their beliefs about family and government obligations. These differences are primarily associated with ethnicity and the relationship of the caregiver to the care recipient.*

Findings from this study add to a large body of literature that has documented the diversity of caregivers. With the exception of ethnicity and geographic location, the demographic characteristics of caregivers included in the ADDGS studies were similar to those of caregivers included in most other studies of caregiving and respite use. Almost three-quarters of the caregivers were female. Approximately 37% were spouses and 46% were adult children (see Conclusion Appendix for full description). Just over 10% of the caregivers were more distant relatives. Consistent with the goal of the ADDGS demonstration to serve minority and rural populations, a much larger proportion of the caregivers in the ADDGS than in other samples of caregivers were Black/African-American (32%), Hispanic/Latino (8%) and just over 53% resided in rural areas.

**Generational Differences**

A number of characteristics that distinguish spouse caregivers from those who are adult children or other relatives are important in terms of differences in expectations, service needs and delivery systems. First, almost all spouses lived with the care recipient and they resided in a household that included only the caregiving dyad. In contrast only 63% of adult children and 35% of other relatives in this study resided with the care recipient. Second, only a few spouses were employed outside of the home, while 52% of adult children were employed outside of the home. Third, past research has noted that spouses tend to spend a greater number of hours providing care and the care that they provide tends to be more intense including more personal care (Montgomery & Kosloski, 2000). This pattern was also observed for the caregivers in the ADDGS study by many of the providers who participated in the interviews. Fourth, spouses reported a higher level of affection for the care recipient and a greater sense of obligation to provide care than did adult children or other caregivers. Finally, at the time that spouse caregivers entered the demonstration program seeking services, they had been providing care for a longer period of time and were caring for elders who were more significantly impaired. The mean length of caregiving for spouse caregivers in the longitudinal sample was 45 months, while the mean length of caregiving for adult children was 39 months. The mean ADL score at intake was 4.4 for elders assisted by spouses in contrast to 3.8 for elders assisted by adult children. Similarly, elders cared for by spouses had a mean score of 13.4 on the measure of problem behaviors as opposed to 13.1 for elders with an adult child caregiver.

**Gender Differences**

Although this project did not assess gender differences in caregiving behaviors, past research has noted gender differences with respect to caregiving tasks that may well account for differences in patterns of respite use that were observed in this study. While the majority of previous studies have reported no gender differences in the level of affection for the care recipient or in obligation to provide care, significant differences between males and females have been observed in the amount and type of care provided especially among adult children caregivers. In general, female caregivers provide a greater amount of care and more intense care than do males. In contrast,

males tend to seek and obtain more assistance with their caregiving tasks than do women (see Montgomery & Kosloski, 2000 for a review of this literature).

### **Ethnicity**

Cultural differences were observed in key demographic characteristics of the study samples and in beliefs about the appropriate roles of family and government for providing long term care. Both types of differences appear to have implications for service delivery. Among Whites, spouses are much more likely to be the primary care provider. In contrast, adult children are more prevalent as caregivers for other ethnic groups especially Black/African-Americans. Consequently, care recipients from these minority groups are more likely to reside in larger households and their caregivers are more likely to have another person available for back-up assistance. This is especially true for Hispanic/Latinos who also report greater satisfaction with the level of social contact they have, and the help that they receive from their informal support network than do either Black/African-Americans or Whites.

In general, the beliefs expressed by both Black/African-American and Hispanic/Latino caregivers about long term care differ significantly from those of Whites. Caregivers from the two minority groups expressed a greater affection and respect for the care recipient and higher levels of religiosity. Also Black/African-Americans reported greater reliance on religion and religious groups for emotional support. At the same time, when directly asked, caregivers from both minority groups expressed greater expectations for help from government sources and less guilt in receiving help from outside sources. This finding is somewhat perplexing given the consistent reports among service providers that minority groups are skeptical users of government services.

## **2. PATTERNS OF RESPITE USE**

*Diversity among caregivers created a corresponding diversity in the types of services that caregivers seek and the manner in which they use respite services.*

Clear patterns were observed that indicate that caregivers seek and continue to use services that they perceive as useful to their caregiving context. Similarly, caregivers ceased using services that they perceived to be inappropriate or difficult to use. Indeed, almost one third of the clients included in this study were brief users who used services for only one or two months.

### **Day Care Services**

In general, this set of studies support the conclusion that most day care centers have limited capacity to care for persons who exhibit problem behaviors or who have high functioning impairments. Day care is more often used for extended periods when the caregiver is an adult child who must be away from home or who has other family obligations. These caregivers are caring for less impaired elders who engage in fewer problem behaviors. Many of the day care users are seeking a respite program that will allow them to maintain their employment outside of the house. These employed caregivers are most likely to continue to use day care steadily for longer periods of time. However, adult children also need services to be available consistently throughout the week for extend periods of time. Hence, brief use was also more prevalent when programs placed stricter limits on the number of hours of care available to a client.

Consistent with the of greater prevalence of adult children as caregivers among minority groups, both Black/African-American and Hispanic/Latino caregivers are more likely to use day care services than are Whites, and are less likely to be brief users of the services. Finally, the patterns of respite use reflect gender differences in use of formal supports. When the primary caregiver is a son rather than a daughter, the elders use more day care. Similarly when the primary caregiver is a wife rather than a husband, the elder uses less day care.

### **In-home Services**

In-home services tend to be the first choice of spouse caregivers. Caregivers who have been providing care for the longest periods of time for elders who have greater levels of impairment use in-home programs. For many users of in-home services, day care programs are not sufficient to meet their needs. Most often persons using in-home care

for any extended period of time seek programs that offer personal care and professional staffing. It is also noteworthy that like day care, in-home services are used in greater quantities by male caregivers.

The absence of ethnic differences in patterns of in-home use probably reflects the high level of need among those who use in-home respite services. For those persons who use in-home services, the need for care outweighs most other factors, such as program characteristics, which might affect the duration or intensity of use.

Finally, it is important to note that the highest intensity of use is observed among middle-income caregivers (\$30,000 to \$50,000). Because this pattern is inverse to that observed for nursing home use, it suggests that use of in-home services is influenced by the relative cost to families of in-home care as compared to nursing home care. For families with incomes in the mid range, in-home services may be the least expensive form of long-term care. The cost of nursing home placement can be prohibitive and therefore these middle-income families may use higher quantities of in-home services to help them delay placement of a highly impaired elder. In contrast, families with greater resources can often afford the costs of nursing homes when elders have high levels of care needs. Similarly, families with the lowest incomes are eligible for Medicaid and, thus, can afford nursing home care. At the same time, however, Medicaid does not generally cover in-home services so these families may not have the option of using in-home services. In short, the costs of long term care that must be borne by families appear to be a structural factor that influences service utilization.

### **3. VALUE OF MULTIPLE FORMS OF RESPITE PROGRAMS**

*A variety of types of respite services are needed to meet the requests of different service populations. The distinct patterns of service use that were observed for different segments of the caregiving population underscore the importance for communities to offer a respite services in an array of formats. Optimally, a community would offer a full continuum of services.*

Caregivers are active agents in choosing support services. The patterns of respite use observed in the longitudinal data suggest that the choices that caregivers make are influenced by both structural factors and by caregivers' perceptions of their own needs.

Many adult children caregivers are dealing with multiple family obligations which often include being the primary breadwinner. These caregivers need a day care program that will fully relieve them of caregiving tasks while they are at work. In-home programs tend to be too expensive to meet the needs of this group and group day programs do not offer the consistency of care that is required.

For some caregivers, respite programs provide an important and useful break from their caregiving activities. If the elder is only mildly impaired, a group day care program offered on a weekly or bi-weekly basis may be quite sufficient. If, however, the elder is more impaired or engages in too many problem behaviors, day care use may be inappropriate. Caregivers assisting these more highly impaired elders may find short, regular in-home visits to be useful.

Among users of in-home services there can also be variation in the care levels that are required. For the most impaired elders, caregivers are concerned that volunteers may not have the level of skills required to care for the elder. Therefore family members providing high levels of care may shy away from programs that use volunteers.

Finally, findings from the analysis indicate that many caregiving situations change over time and caregivers need the opportunity to transition to more appropriate types and levels of care. If the appropriate level or type of care is not available, caregivers often choose to abdicate the caregiving role. This is especially true for adult children who are more likely to have competing demands in their lives.

The variety of needs among caregivers and the diversity of caregiving situations underscore the value of multiple forms of respite in a community. Without multiple types and levels of care, many families will go unserved or under-served. When programs are not available in the right form, caregivers either do not use any services or they use

services for only a brief period. Not all respite is equal and no program can adequately serve the full diversity of caregivers in a community.

#### 4. THE INFLUENCE OF PROVIDER CHARACTERISTICS

*Provider characteristics influence the patterns of use or non-use of services as well as client satisfaction with services. When making decisions about service use, families judge the **appropriateness** of a service for their family context and the **accessibility** of the service.*

Previous studies of respite care have given little attention to the influence of provider characteristics on patterns of service use. Although the functional level of the elder and the caregiving context largely define the needs of a family for different levels of service, findings from all three studies underscore the impact of provider characteristics on the ability and willingness of families to use services. This series of studies identified three sets of provider characteristics that influence clients' service use, *the amount and level of service, quality of staff, effective communication with family members.*

##### **Appropriate Targeting of Services**

As noted above, respite programs must match the level of care provided to a client's level of functioning. Services that are limited in capacity such that they can provide care for only high functioning or only low functioning clients automatically restrict their potential client pool. To successfully serve caregivers, it is important for providers to recognize this limitation.

In addition to the level of care offered, appropriateness of a service can also be determined by the amount of service made available. Programs that offer only a limited number of hours of care are not appropriate for families caring for highly impaired elders or caregivers with employment responsibilities.

Cost counts, but it is not necessary to make all services free. In fact, many providers noted that there was a stigma associated with free services for many families who perceived them as welfare. Sliding scale fees and co-payments can also help providers

make many services available in sufficient quantities. However, when the level of service that is needed requires professional workers who can provide health care services, it is important to identify set fee structures so that families can incorporate these costs into their budgets in a planned manner.

Finally, caregivers are more willing to use day care programs that include activities, music and food that are familiar to the client.

### **Quality of Staff**

Caregivers also make judgments about the quality and appropriateness of staff members, which influences their willingness to use services. There is a clear preference for workers who are knowledgeable about the disease process and community resources, sensitive to the values and cultural background of the family, respectful of the elder, and friendly and easy to talk with.

When well-trained workers who demonstrate sensitivity and respect staff respite programs, families tend to trust them and be more satisfied with the programs. Although the employment of workers who are similar in ethnic background to clients can expedite the creation of trust for the worker, such similarity is not a requirement for a successful program. Caring, skilled staff members of any cultural background can be trained to understand different cultural views and communicate well with families.

### **Effective Communication**

Effective communication that clearly informs caregivers about the nature of program services is an essential component of a respite program that is judged satisfactory by clients and providers. The most consistent finding regarding client satisfaction with services centered on the value of clear communication. Regardless of the cultural background, the relationship of the caregiver to elder, or geographic location, caregivers were most satisfied when they were able to communicate clearly with staff members and when they had clear expectations about the services to be provided and how to obtain them.

Effective communication, however, goes beyond a common language. Although the employment of bilingual staff members can be very important for the Hispanic/Latino populations for whom English is often a second language, good communication entails much more. Family members are most satisfied when workers use non-technical language, listen carefully to families' needs, and demonstrate openness to an exchange of information.

It is also extremely important that families clearly understand the responsibilities and expected behaviors of workers. This is especially true for in-home workers for whom families may have very unrealistic expectations. Satisfaction comes when workers' behaviors match the families' expectations. Therefore it is important to clarify these expectations at the outset. It is also important to make services easily accessible to families by helping them communicate their needs and receive the services of the type and quantity they desire.

Finally, families need to be reassured that respite programs are not a replacement for their own efforts. Programs that work with family members as team members tend to be perceived as more appropriate.

## **PRACTICE AND POLICY IMPLICATIONS**

When the broad array of findings is considered together, several general implications for program design and service delivery can be delineated.

1. The efficient and effective use of program resources dictates careful consideration of patterns of service use for different segments of the target population. These studies identified a range of different long term patterns of service use that are associated with the relationship of the caregiver to the elder and with ethnicity. To plan for future service needs, it is important to consider these trajectories in conjunction with the prevalence of the different segments of the population in the programs' catchment area.

2. When developing a new respite program, it is important to create a service that complements other services available in the community in an effort to make a full continuum available. Not all programs are appropriate for all caregivers. If a community can offer only one form of respite, providers need to learn as much as possible about the prevalence of different types of caregiving contexts in the community to best meet the community's needs.
3. Existing programs may want to carefully consider the characteristics of the clients they are currently serving and note the characteristics of those who are going unserved. All policy decisions regarding availability of services reflect values about who should be served and at what cost. It is not always possible for programs to serve all segments of the caregiving population. However, it is important for policy makers to consciously consider which groups of persons they choose to serve. For example, day care programs that are not offered daily or throughout the normal workday clearly will not serve the majority of employed caregivers. A well-planned program will consider such issues carefully.
4. Once a respite program has been developed, it is important to target the service to the appropriate segments of the caregiving population. Programs that carefully target services and/or alter eligibility rules or the number of hours of service available will be able to reduce the number of families that enroll in services for only brief periods. These families can be costly to programs due to the high costs associated with initial enrollment of clients.
5. The hiring and training of competent, caring workers is a key element in creating a successful respite program. All staff members should be trained to be sensitive to the diversity of caregiving situations and to communicate with families in an open, effective, and clear manner. Existing programs might want to assess the communication skills of their staff members and/or modify the ways in which they communicate information about the services to families. Attention needs to be given to both the content of communications and the way in which information is delivered. Clarity is essential.

6. Careful consideration should be given to policy decisions that place limits on access to respite services. For example, the level at which services are capitated clearly influences service use. Not all families benefit from the same dosage or amount of respite and it is possible for programs to be ineffective because the amount of service offered is insufficient.

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